DOCUMENT RESUME

ED 426 554 EC 306 990

AUTHOR	Campbell, Janet; Cawthon, Laurie; Keenan, Trisha; Lyons, Dorothy; Schrager, Laura
TITLE	Evaluation of Early Intervention in Washington State: Options and Issues.
INSTITUTION	University of South Florida, Tampa. Dept. of Gerontology.
PUB DATE	1998-07-00
NOTE	202p.; For related document, see EC 306 991.
AVAILABLE FROM	Research and Data Analysis, Department of Social and Health Services, Olympia, Washington 980504-5204; Report Number 7.95a.
PUB TYPE	Information Analyses (070) -- Reports - Research (143)
EDRS PRICE	MF01/PC09 Plus Postage.
DESCRIPTORS	Cross Sectional Studies; Developmental Delays; *Disabilities; Early Intervention; *Exceptional Child Research; Infants; Longitudinal Studies; Models; Objectives; *Outcomes of Education; *Program Effectiveness; *Research Design; *Research Methodology; State Surveys; Statistical Analysis; Toddlers
IDENTIFIERS	Washington

ABSTRACT

This report describes options for study designs to evaluate the effect of early intervention on infants and toddlers, birth to three, with disabilities or developmental delays and their families in Washington state. Information was gathered from extensive literature reviews, a survey of local assessment efforts in Washington, a technical data inventory, and a consultation with stakeholders such as service providers, agency personnel, the Office of Superintendent of Public Instruction, parents, and community supporters. Recommendations include: (1) using a small- scale longitudinal study, retrospective cross-sectional study, or a key informant study for early intervention research; and (2) using an integrated research plan that logically and methodically addresses: who the children and families are who are receiving services, what are their needs, how services are addressing the needs of children and families, and what child and family outcomes occur as a result of service provision. Appendices include information on child and family characteristics, a local assessment survey, state and national early intervention goals, and possible statistical models for using subjects as their own control. (Contains over 150 references.) (CR)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 426 554

Evaluation of Early Intervention in Washington State

Options and Issues

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY

T. BROWN

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

1

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Washington State Department of Social and Health Services
Research and Data Analysis
Infant Toddler Early Intervention Program

BEST COPY AVAILABLE

EC306990

Evaluation of Early Intervention in Washington State:

Options and Issues

Janet Campbell, Ph.D.
Laurie Cawthon, M.D., M.P.H.
Trisha Keenan, M.A.
Dorothy Lyons, M.P.A.
Laura Schrager, M.A.

July 1998

Research and Data Analysis
Department of Social and Health Services
Olympia, Washington 98504-5204

DEPARTMENT OF SOCIAL AND HEALTH SERVICES

Lyle Quasim, Secretary

MANAGEMENT SERVICES ADMINISTRATION

Ken Harden, Assistant Secretary

RESEARCH AND DATA ANALYSIS

Elizabeth Kohlenberg, Ph.D., Acting Director

DIVISION OF DEVELOPMENTAL DISABILITIES

Timothy R. Brown, Ph.D., Director

INFANT AND TODDLER EARLY INTERVENTION PROGRAM

Sandy Loerch, Program Director

ADVISORY GROUP

Nancy Anderson, M.D., M.P.H., DSHS/Medical Assistance Administration
Nancy Fisher, R.N., M.D., M.P.H., DSHS/Medical Assistance Administration
Jean Kelly, Ph.D., University of Washington
Katy Middleton, B.S., Parent
Paulette Mills, Ph.D., Washington State University, Pullman
Judith Moore, M.A., Boyer Children's Clinic
Charles Peck, Ph.D., Washington State University, Vancouver
Susan Sandall, Ph.D., University of Washington
Kristine Slentz, Ph.D., Western Washington University
John Stull, M.D., M.P.H., Oregon Health Sciences University

PROGRAM STAFF

Lou Colwell, Ed.D., Office of Superintendent of Public Instruction
Deborah Lee, Ph.D., R.N., Department of Health
Babs Roberts, Infant Toddler Early Intervention Program

When ordering, please refer to
Report Number 7.95a

ACKNOWLEDGMENTS

This report was prepared for and funded by the Infant Toddler Early Intervention Program (ITEIP), Division of Developmental Disabilities (DDD), Department of Social and Health Services (DSHS).

Sincere thanks go to the members of the Child and Family Early Intervention Outcome Measures Planning Project Advisory Group who provided careful, thoughtful review, commentary, and direction. While Research and Data Analysis (RDA) is grateful for the assistance of the Advisory Group, RDA researchers are primary authors and assume full responsibility for any omissions or misstatements contained in the report.

Special thanks go to the individuals from child developmental programs, County Interagency Coordinating Councils, Educational Service Districts, Infant Toddler Early Intervention Program Lead Agencies and additional contractors, neurodevelopmental centers, school district Special Education Directors for schools who currently serve children, tribal authorities, University Affiliated Programs, and University Special Education Teacher Preparation Programs who completed the local assessment survey forms. Appreciation goes to the research investigators who responded to the request for information on research studies being conducted on early intervention in Washington State including Kathryn Barnard, Cathryn Booth, Rodd Hedlund, Coleen Morisset Huebner, Susan Janko, Jean Kelly, and Susan Spieker.

For information, materials, and feedback, special thanks goes to Myriam Baker, Researcher, Colorado Foundation for Families and Children; Maryanne Barnes, Executive Director, Tacoma Learning Center; Michael Conn-Powers, Institute for the Study of Developmental Disabilities, Indiana University-Bloomington; Ellen Frede, The School of Education, The College of New Jersey; Michael Gamel-McCormick, Center for Disabilities Studies, University of Delaware; Kathy Hebbeler National Early Intervention Longitudinal Study, Stanford Research Institute (SRI) International; Susan Janko, College of Education-Special Education, University of Washington; Deborah Montgomery, American Institutes for Research; Jeff Priest, Early Childhood Research Institute on Measuring Growth and Development, University of Minnesota; Richard N. Roberts, Director, Early Intervention Research Institute, Utah State University; Beppie Shapiro, University of Hawaii at Manoa.

Elizabeth Kohlenberg, Acting Director of RDA, DSHS, provided oversight and overall project management.

Sincere thanks go to Karen Thorson, who designed the cover of the report, and helped with the layout, details, and organization of the report; Jason Fry, Francia Reynolds and Greg Kirkpatrick for maintaining the RDA computer network, a system that meets the diverse demands of RDA's managers, researchers, analysts, programmers, and talented support staff.

TABLE OF CONTENTS

EXECUTIVE SUMMARY ix

CHAPTER 1: INTRODUCTION 1
Background 1

CHAPTER 2: METHODS 9
Preliminary Background Research 9
Input from Stakeholders 10
State Interagency Coordinating Committee 11

CHAPTER 3: DEVELOPMENT OF FAMILY AND CHILD OUTCOME MEASURES AT THE FEDERAL LEVEL 13
Introduction 13
National Early Intervention Longitudinal Study (NEILS) 13
Early Childhood Research Institute on Measuring Growth and Development (ECRI-MGD) 17
Consortiums 20
Early Intervention Research Institute (EIRI) 1986-1995 24
Summary 26

CHAPTER 4: DEVELOPMENT OF FAMILY AND CHILD OUTCOME MEASURES AT THE STATE LEVEL 29
Introduction 29
Implementation Studies 31
Research Studies 32
Feasibility/Exploratory Studies 34
Summary 36

CHAPTER 5: LOCAL ASSESSMENT IN WASHINGTON STATE 37
Local Assessment Activities 37
Research Studies 39

CHAPTER 6: DATA INVENTORY 45
Data from Office of Superintendent of Public Instructions/Student Files 45
Data from Division of Developmental Disabilities Files 46
Data from Department of Health Files 46
First Steps Database 46

CHAPTER 7: STUDY DESIGNS 51
General Literature Review 51
Methodological Challenges 55
Study Design Options 62

CHILD/FAMILY SERVES AS OWN CONTROL-LARGE SCALE LONGITUDINAL STUDY 63
CHILD/FAMILY SERVES AS OWN CONTROL-SMALL SCALE LONGITUDINAL STUDY 81
COMPARISON GROUP-LONGITUDINAL STUDY 92
PRE-POST STUDY 100
RETROSPECTIVE CROSS-SECTIONAL STUDY 108
KEY INFORMANT SURVEY STUDY 122

CHAPTER 8: DISCUSSION AND RECOMMENDATIONS 137
Recommendations 138
Discussion 139

CHAPTER 9: FUTURE DIRECTIONS
RECOMMENDATIONS FOR WASHINGTON STATE 145
Introduction 145
Discussion 146
Washington State Recommendations 149

REFERENCES 157

APPENDICES 169

Appendix A Biosketches 173
Appendix B Child and Family Characteristics (Background Variables) 177
Appendix C Local Assessment Survey 179
Appendix D State and National Early Intervention Goals 181
Appendix E Statistical Models for Using Subjects as Their Own Control 195

The LITERATURE SUMMARY is available upon request from Research and Data Analysis, Department of Social and Health Services, (360) 902-0713

INDICATORS FOR CHILD AND FAMILY OUTCOMES

CHILD OUTCOMES/INDICATORS	FAMILY OUTCOMES/INDICATORS
Developmental Skills * cognitive development * communication * social competence (social/emotional) * adaptive (level of independence) * physical (motor, vision, hearing) **Health** * children have the best possible health **Readiness to Learn** * confidence * curiosity * persistence * capacity to communicate * capacity to get along with others **Child-Parent (Primary Caregiver) Interaction** * reciprocity * responsivity	**Knowledge** * knowledge of child's disability * understanding what the child needs to enhance development * ability to read child's cues **Empowerment** * confidence in ability to enhance child's development * confidence in ability to interact with professionals and advocate for services * locus of control **Parent (Primary Caregiver)-Child Interaction** * reciprocity * responsivity **Support** * family has economic resources * family has social support **Impact of Early Intervention** * perceived impact of services on child * perceived impact of services on family * perception of services delivered

EVALUATION OF EARLY INTERVENTION IN WASHINGTON STATE: *OPTIONS AND ISSUES*

EXECUTIVE SUMMARY

This report describes options for study designs to evaluate the impact of early intervention on infants and toddlers, birth to three, with disabilities or developmental delays and their families, one of Washington State's most vulnerable populations.

Information was gathered from an extensive literature review, a survey of local assessment efforts in Washington State, a technical data inventory, and consultation with stakeholders such as service providers, agency personnel (Department of Health, Department of Social and Health Services, and the Office of Superintendent of Public Instruction), parents, and community supporters. Research and Data Analysis convened an advisory group to provide professional expertise in reviewing and commenting on materials prepared for this project.

The project was funded by the Department of Social and Health Services (DSHS), Infant Toddler Early Intervention Program (ITEIP). Its intent was to develop study designs to meet the evaluation goals of parents, the Joint Legislative Audit and Review Committee (JLARC), ITEIP, and stakeholders.

OUTCOMES

The study designs, and their associated child and family outcomes, are intended to address the question: *what is the impact of early intervention services on children, birth to three, with disabling or delaying conditions and their families in Washington State?* The range of outcomes chosen for the child and the family and indicators are listed on the previous page. The particular design of the study determines which outcomes are selected for that study.

STUDY DESIGN OPTIONS

Research on the effectiveness of early intervention involves a variety of methodological challenges. The absence of a control group presents the greatest problem. If subjects cannot be randomly assigned to treatment (early intervention) and non-treatment (no early intervention), it is difficult to conclude that changes in child/family outcomes are due specifically to early intervention. To control for effects on outcomes from factors other than early intervention, characteristics which affect child/family outcomes must be taken into account.

The main study designs are as follows:

STUDY DESIGN TYPES

- Child/Family Serves as Own Control—Large Scale Longitudinal Study
- Child/Family Serves as Own Control—Small Scale Longitudinal Study
- Comparison Group—Longitudinal Study
- Pre-Post Study
- Retrospective Cross-sectional Study
- Key Informant Study—Survey-only and Three-tiered Approach

Design options include the use of each child/family as its own control, which means there is no control or comparison group. These studies essentially measure changes in each individual and family that have occurred during the course of intervention, and compare beginning outcome data to outcome data at future points in time for each subject. Other studies seek to identify appropriate comparison groups. Some design options use perceptions of key informants and information provided in state data bases.

OUTCOME STUDY RECOMMENDATIONS

- Research and Data Analysis and the Advisory Group were in agreement in recommending the design, Child/Family Serves as Own Control—Small Scale Longitudinal Study.

  While this study design offers many advantages, its estimated direct cost, at least $1.4 million, and the availability of results, not before the year 2004, caused Research and Data Analysis and the Advisory Group to include lower cost options that would provide more timely results.

  If budget and timeliness are constraints:

- Research and Data Analysis recommends the Retrospective Cross-sectional Study as a less expensive and shorter timeline option.

- The majority of the Advisory Group recommends the Key Informant Study—Three-tiered Approach.

GENERAL RECOMMENDATION

The need for a more comprehensive alternative approach to evaluation of early intervention in Washington became evident during the process used to complete this report. On the basis of all the information gathered during this process, Research and Data Analysis recommends:

- **An integrated research plan that logically and methodically addresses four questions:**

  ⇒ Step One: Who are the Children and Families Receiving Services?

  Use enhanced profiles in annual child count to describe the children and families who are receiving early intervention in Washington State.

  ⇒ Step Two: What Are Their Needs?

  Conduct a needs assessment of children and families who are receiving early intervention services in Washington State using focus groups, interviews, and surveys.

  ⇒ Step Three: How Are Services Addressing The Needs of Children and Families?

  Conduct a review of program services provided to children with disabling or delaying conditions and their families in Washington State using monthly service reports and program observation.

  ⇒ Step Four: What Child and Family Outcomes Occur as A Result of Service Provision?

  Conduct an outcome study which identifies positive child and family outcomes occurring as a result of early intervention services in Washington State.

In evaluating early intervention services, decision makers should determine what specific information they seek, at what price, and how long they wish to wait for the results. Once these parameters are defined, the information presented in this report can be used to make a well-informed decision as to how to evaluate early intervention services.

CHAPTER 1

INTRODUCTION

This report describes options for study designs to evaluate the impact of early intervention on infants and toddlers, birth to three, with disabilities or developmental delays and their families, one of Washington State's most vulnerable populations.

The *Child and Family Early Intervention Outcome Measures Planning Project* is funded by the Department of Social and Health Services (DSHS), Infant Toddler Early Intervention Program (ITEIP). This project's intent was to develop study designs to meet the evaluation goals of parents, the Joint Legislative Audit and Review Committee (JLARC), ITEIP, and stakeholders. This report presents a range of study designs with outcome measures, data sources and methods needed to accomplish them, and their approximate costs.

It is hoped that the outcome measures and study designs presented here will enhance planning and discussion at the state and local levels, and facilitate decision making and priority setting for Washington's early intervention programs for infants and toddlers and their families. In addition to the outcome measures and study designs, summaries of our preliminary background research are presented in the separate appendix, Literature Summary, and in this report. These include the literature summary (separate appendix), local assessment (Chapter 5), and data inventory (Chapter 6).

BACKGROUND

With the passage of the Education for All Handicapped Children Act (Public Law 94-142) in 1975, later retitled the Individuals with Disabilities Education Act (IDEA), the educational rights for all school-age children with disabilities, ages 6 through 18, were ensured. Within this law were incentives for including preschool-age children. This legislation evolved from various state statutes and federal court cases based on the United States Constitution (Martin et al., 1996).

Policy makers at the federal level, recognizing the importance of early referral and intervention for children with disabilities and developmental delays ages birth to five, passed the 1986 amendments to Public Law 99-457 later known as the Individuals with Disabilities Education Act (IDEA). Part B of IDEA extends rights to children with disabilities, ages three to six.* Part H of IDEA offers states federal incentive funds to plan, develop, and implement a statewide system of coordinated interagency programs for infants and toddlers with disabling or delaying conditions, birth to three years of age, and their families. The Part H program in Washington State is named the Infant Toddler Early Intervention Program (ITEIP). The Governor designated DSHS as the lead agency for Part H federal funds. The five participating state agencies include DSHS; Department of Community, Trade and Economic Development; Department of Health; Department of

* In this report, three to six indicates children who are three years or older, and less than six years of age. (Office of Superintendent of Public Instruction refers to these children as 3 to 5 year olds.)

Services for the Blind, and Office of the Superintendent of Public Instruction. In October 1994, Washington State began full implementation of Part H. As of July 1998, Part H will be titled Part C.

In Washington State, 5,007 infants and toddlers under three years of age were determined to be enrolled in public early intervention services for delaying or disabling conditions as of December 1, 1997 (Lyons et al., 1998). Infants and toddlers with disabilities and their families are eligible to receive an array of public early intervention services although all may not seek enrollment in state programs. Public early intervention services for children birth to three with delaying or disabling conditions are provided by child development centers, county health and human service agencies, educational service districts, neurodevelopmental centers, school districts, tribal programs, and other local and state agencies. The Individuals with Disabilities Education Act (IDEA), Part H program acts as an umbrella and provides linkages and enhancement of these services to ensure a statewide system of comprehensive, multi-disciplinary, coordinated services to infants and toddlers with disabilities and their families.

In the *Birth to Three Years Study* (Harding and Keating, 1995), the Legislative Budget Committee (now called the Joint Legislative Audit and Review Committee, JLARC) and the Washington State Institute for Public Policy (WSIPP) recommended that the legislature conduct an evaluation of the Part H program and that the Department of Social and Health Services and the State Interagency Coordinating Council develop outcome measures and begin tracking the necessary data to document these measures.

Measurement of Impact of Part H and Early Intervention Services

In the early stages of this project many long discussions including those with the Advisory Group revolved around whether the most appropriate response to JLARC's recommendation was to measure the impact of Part H or the public early intervention services. It was decided that these questions could not be separated, in that Part H is an integral part of early intervention services in Washington State.

Measures of Success

Neurophysiological Basis of Future Development

A new consensus about the importance of intervening in the first months and years of life is emerging in the field of early intervention for children with established disabilities or developmental delays and those at risk biologically or environmentally (Guralnick, 1998). In 1997 House Resolution 131 was submitted entitled *Zero to Three Resolution for Early Childhood Development*, expressing the consensus of the House of Representatives that sufficient funding should be provided to meet the needs of infants and toddlers through five programs including Part H of Individuals with Disabilities Education Act (IDEA). This resolution acknowledged the critical nature of the first three years of life: "groundbreaking scientific research shows that children's experiences during their first three years of life determine how the intricate circuitry of their brains are 'wired' and lay the foundation for their future development."

This statement is indeed borne out in the research literature which shows that during infancy and early childhood the connections between neurons in the brain, or neural synapses, reach their highest density, well above that of adults, and remain at that level until late childhood (Chugani et al., 1987; Huttenlocher, 1990). This is a period of great potential, for it is sensory experience that helps determine the pattern of wiring between the neurons in the brain (Greenough and Black, 1992; Weiler et al., 1995). This link between brain activity and brain structure points to the importance of the critical early years of life.

Child Development and Parent-Child Relationship

What the brain learns determines the individual child's responses to the environment. The sensory experience that embodies success to an infant or toddler and lays the foundation for future learning may be the gentle and kind touch of her mother, the extended gaze of his father, the soft, soothing voice of his caregiver, and never being taught to feel less than her full potential. Research studies report the long-term significance of the early parent-child relationship and its power to facilitate a child's successful development (Ainsworth, 1973; Bowlby, 1969; Lyons-Ruth and Zeanah, 1993; Tjossem, 1976). Feeling loved and valued and knowing that their needs matter and will be met foster the development of trust, self-confidence, curiosity, and empathy (Carnegie Task Force on Meeting the Needs of Young Children, 1994). With this foundation, these infants and toddlers are then free to explore and discover. Understanding a child's responses and development is necessary for families to actively support the child in these endeavors.

Part H

This concept of the critical importance of parents and other caregivers is reflected in the vision and goals of Individuals with Disabilities Education Act (IDEA), Part H. The delivery of family-centered early intervention services required by Part H relates to the new direction in early intervention which focuses on enhancing the quality of early parent-infant interactions (Bennett and Guralnick, 1991). One of the general state program goals per the national legislation for IDEA, Part H (1997) is "a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler."

The general goals of Washington's Infant Toddler Early Intervention Program (Part H) include the coordination of development and implementation of interagency and multidisciplinary delivery of early intervention services which enhance the development of each infant and toddler with disabilities; provide services that the child's family defines according to the family's concerns, priorities, and resources; and provide family support for enhancing the child's development.

Family Measures of Success

Underlying the focus on a family-centered approach is the established fact that the quality of the early parent-child relationship is related to child development and will affect child outcomes whether they are measured at three years of age or at six years of age. For many researchers the focus has shifted to determining what the family outcomes in early intervention would be from this family-centered approach. Bailey and his colleagues (1998) are among the principal investigators for the National Early Intervention Longitudinal Study (NEILS) involving twenty states. Their recent publication suggests eight questions as a framework for the assessment of family outcomes from early intervention. These questions focus on family perceptions of the early intervention experience and on the impact on the family. Questions designed to assess the impact on the family include focus on the extent to which early intervention fosters parents': 1) perceived competence as caregivers; 2) ability to work with professionals and advocate for services (empowerment), 3) informal social and community support systems; 4) quality of life; and 5) optimism for a positive future, which Turnbull and Turnbull (1997) point out requires early interventionists' promotion of an optimistic perspective by acknowledging positive possibilities for the toddler and encouraging "great expectations."

Measures of success that emerged from input we received from individual parents and family members of children with delaying or disabling conditions were quality of parent-child interaction, information about child's disability, a sense of hope, adequate information to make decisions, inclusion of parent's perspectives of the outcomes on the Individualized Family Service Plan (IFSP), and knowledge of specific techniques to enhance their child's development at home.

Child Measures of Success

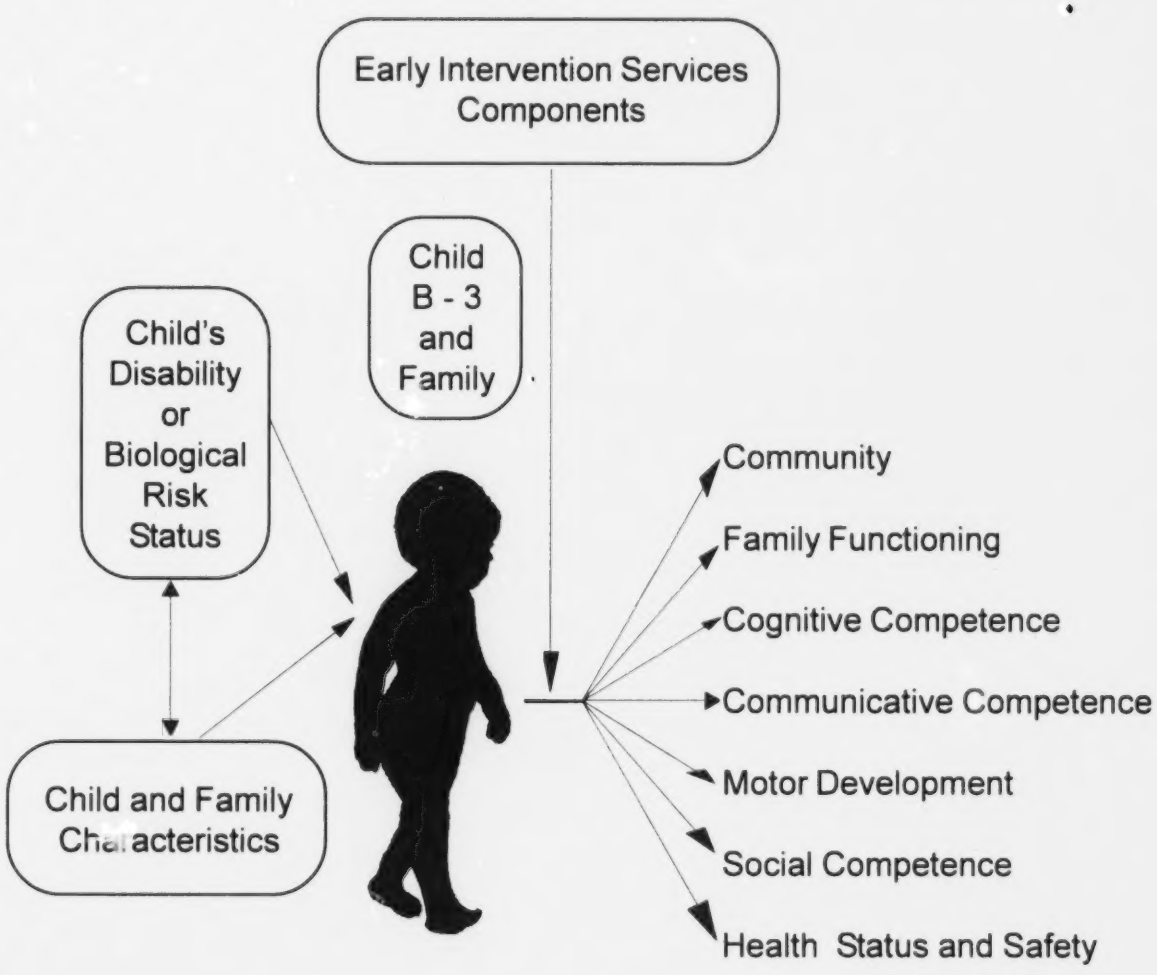
Traditionally, changes in cognitive development, measured by standardized tests, were believed to be the most important measure of success. A general decline in the intellectual development of children with established disabilities and those at risk occurs in the absence of early intervention. Unequivocal evidence now exists that this decline can be substantially reduced by interventions implemented during the first 5 years of life (Guralnick, 1998).

Outcome measures from the primary domains of cognitive, language, affective, and motor development should be expanded to include measures that reflect a broader vision of the goals of early intervention such as social competence and improvement of children's health status (Guralnick and Neville, 1997). Peck et al. (1993) and Billingsley et al. (1996) suggest a more global measure—participation in valued roles, activities, and settings—which includes the related and more specific outcomes of memberships, relationships, and skills.

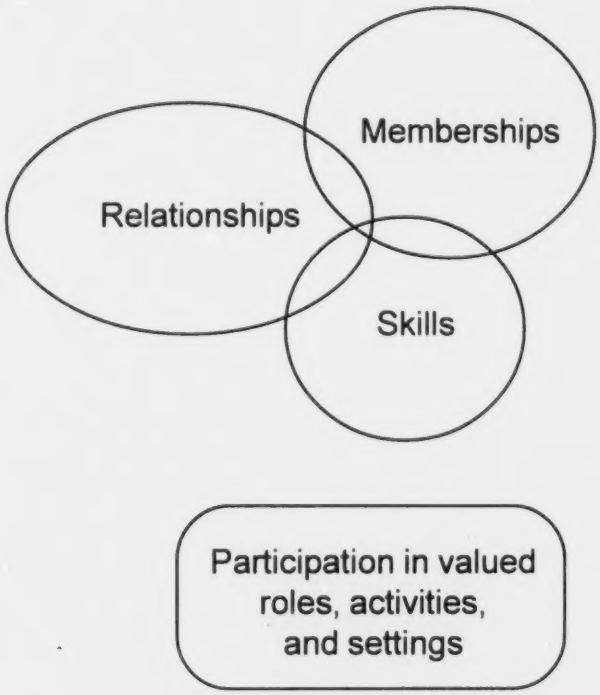
Children's capacity for development is facilitated in the context of secure attachments, consistent, warm nurturing relationships with caregivers, stimulating environments, including a variety of developmentally appropriate toys and materials; quality social contact with other adults and children; a general state of health; and a safe environment

(Guralnick, 1998). Parents and other adult caregivers play critical roles in the child's development during these early years (Carnegie Task Force on Meeting the Needs of Young Children, 1994; Shonkoff et al., 1992). Measuring success requires a framework which includes both child and family outcomes and considers the factors in the conceptual model presented on the following two pages.

CONCEPTUAL MODEL



FOR IMPACTS OF EARLY INTERVENTION



CHAPTER 2

METHODS

The study designs and outcome measures presented in this report were based on preliminary background research, input from key informants, and the combined years of research experience of the project team.

PRELIMINARY BACKGROUND RESEARCH

Preliminary Background Research included the literature review, local assessment and data inventory.

Literature Review

A literature review of evaluation methods and measures in the child development/early intervention field was performed. This review's intent was to help identify the questions which are most critical, the evaluation methods and measures which have been most successful in assessing the impact of early intervention programs, the currently preferred methodologies in the child development/early intervention field, and major difficulties with alternative evaluation strategies. Over 250 published papers on evaluation of early intervention/child development were reviewed.

The bibliography and literature summary table resulting from this literature review can be found in a separate publication, *Evaluation of Early Intervention in Washington State Literature Summary*. The bibliography notes a wide variety of articles useful in understanding issues of evaluation methodologies and outcomes for children with disabilities and their families. The literature summary table includes some key sources of insight into current evaluation and outcome recommendations and strategies, and examples of recent studies and those currently underway. Lists of child, family, and program characteristics from this literature review were made and are included in Appendix B.

The outcome, parent-child interaction, comes from a specific body of research literature. In this report the use of the word *parent* refers to the primary caregiver if other than the parent.

Local Assessment

The *Local Assessment Survey* (Appendix C) was developed to provide knowledge of procedures being used by communities and programs in Washington State for assessing local early intervention efforts. The survey was mailed to child development centers, County Interagency Coordinating Council (CICC) chairs, Infant Toddler Early Intervention Program (ITEIP) contractors, neurodevelopmental centers, school districts, tribal authorities, and universities requesting information on assessment, tracking, or research efforts being undertaken. Chapter 5 describes this process in greater detail.

Technical Data Inventory

A technical inventory was done to identify available statewide data which could be linked at the individual level to study the impact of early intervention programs. Assessment of the feasibility of collecting this information was investigated.

INPUT FROM STAKEHOLDERS

Advisory Group

The Research and Data Analysis project team convened an Advisory Group to provide professional expertise in reviewing and commenting on materials prepared for this project, developing study designs, and assessing their feasibility. Membership in the Advisory Group included expertise in the areas of genetics, nursing, pediatrics, preventive medicine, research, and Special Education (please see Appendix A for biosketches on individual Advisory Group members).

Parents

Unstructured interviews were conducted with individual parents of children with disabling or delaying conditions, including Cassie Johnston, Parent Participation Coordinator for Washington State. Participation in one of the four State Interagency Coordinating Council *Conversations with Families* and summative information from the other three provided another source of data.

Additional input was received from one of our Advisory Group members who is both a parent of a child who was enrolled in early intervention services and a Family Resource Coordinator.

Service Providers

One of the data sources for the development of outcome measures and study designs was a site visit to the Tacoma Learning Center. Research and Data Analysis staff met with Maryanne Barnes, M.Ed., executive director.

Input was additionally received from a member of the Advisory Group, Judith Moore, M.A., executive director of Boyer Children's Clinic and former Chair of the State Interagency Coordinating Council.

Agency Personnel

Representative input from public agencies in Washington State included members of the Advisory Group from the Department of Health (DOH), Department of Social and Health Services (DSHS), and the Office of Superintendent of Public Instruction (OSPI).

Background research concerning available data in Washington State included informant interviews with potential data sources such as the Department of Health and the Office of Superintendent of Public Instruction.

THE STATE INTERAGENCY COORDINATING COUNCIL (SICC)

The State Interagency Coordinating Council (SICC) for Infants and Toddlers with Disabilities and Their Families was involved in the development of this project beginning with the presentation of the proposal for the *Child and Family Early Intervention Outcome Measures Planning Project* in July 1997, received a status report in April 1998, and reviewed the draft for this report in June 1998.

CHAPTER 3

DEVELOPMENT OF FAMILY AND CHILD OUTCOME MEASURES AT THE FEDERAL LEVEL

INTRODUCTION

This section examines steps taken by the Federal Government to develop early intervention outcome measures for children with disabling and delaying conditions and their families. The Federal Government funds both national studies, which focus on specific outcomes developed by national committees, and state and individual research projects which focus on specific topics in early intervention.

The Federal Government monitors state implementation of early intervention programs. As a condition of state participation in Part H, the lead agency in each state is required to submit annual state data and performance reports which include information on the following: the number of children served under Part H; the number of infants under one year served under Part H; the settings in which services are provided; funding sources; and state monitoring activities [U.S. Department of Education Program Performance Plans (FY1999), 1998]. The Federal Government also has funded implementation research such as the Early Childhood Research Institute's Service Utilization project which described the services provided to infants, toddlers, and preschool children with disabilities and their families across nine communities in three states (Colorado, Pennsylvania, and North Carolina) (Gloria Harbin, Thomas Kochanek, cover letter to report, September 1997, Frank Porter Graham Child Development Center).

At this time, the Federal Government does not require participating Part H states to include child and family outcomes in their annual reports. The Government is, however, developing child and family outcome measures to include as part of a list of Part H indicators through its national longitudinal study, National Early Intervention Longitudinal Study (NEILS) funded by the Office of Special Education Programs, U.S. Department of Education. It can also draw from results of other federally funded projects to determine which child and family outcomes might be appropriate for monitoring long term.

The following federally funded projects include family and child outcomes as an integral part of their studies.

NATIONAL EARLY INTERVENTION LONGITUDINAL STUDY (NEILS)
Status: In progress

General Description

The National Early Intervention Longitudinal Study (NEILS) is a five year longitudinal study designed to provide both descriptive and explanatory information regarding process outcomes and family and child outcomes using the following main study questions:

- Who are the children and families receiving early intervention services?
- What early intervention services do participating children and families receive, and how are those services delivered?
- What outcomes do participating children and families experience?
- How do outcomes relate to variations in child and family characteristics and services provided?

Data will be collected from the following sources:

NEILS: SOURCES AND TYPES OF DATA INFORMATION

DATA SOURCE	DATA TYPES
Telephone interviews with families	child and family characteristics child functioning families' perception of services
Semi-annual reports from service providers	services provided to children and families information on children's transitions
Survey of service providers	their background their training ways they deliver services
Profiles of local state early intervention system elements	elements of delivery system costs
Survey of teachers	progress of NEILS children at age 5 services being provided at age 5
Survey of early intervention program directors	program description

The study will include a nationally representative sample involving three to five counties in twenty states. Approximately 3,800 children will be included. Children between birth and 31 months who are newly entering early intervention will be recruited (1997-1998). The project is being conducted by a national investigative team (Stanford Research Institute International, Frank Porter Graham Child Development Center, Research Triangle Institute, American Institute for Research) and a national advisory panel.

NEILS PROJECT STAFF AND PARTICIPATING STATES

NEILS National Advisory Panel	NEILS Investigators	NEILS Participating States
James Blackman	**SRI International**	Arkansas
Susan Bubb	Kathleen Hebbeler	California
Carl Dunst	Patricia McKenna	Colorado
Mary Elder	Donna Spiker	Florida
Linda Goetze	Mary Wagner	Hawaii
Gloria Harbin		Idaho
Kofi Marfo	**Frank Porter Graham Child**	Illinois
Samuel Meisels	**Development Center**	Kansas
Luzanne Pierce	Don Bailey	Maryland
Aida Ramirez	Lynne Kahn	Massachusetts
Cordelia Robinson	Robin McWilliam	Michigan
Arnold Sameroff	Rune Simeonsson	Minnesota
Nancy Sweet		New Mexico
	Research Triangle Institute	New York
	Susan Kinsey	North Carolina
		Ohio
	American Institutes for Research	Pennsylvania
	Jay Chambers	South Carolina
	Thomas Parris	South Dakota
		Texas

(NEILS web site: http//www.sri.com/policy/cehs/neils/neilprog.html, 3/13/98; NEILS Draft Surveys, February 27, 1997)

Child and Family Outcomes

While specific child and family outcomes and specific analytic methods have not yet been finalized, general outcome measures and data sources have been suggested.

Family outcomes emerged as a result of the work conducted by NEILS investigators. The process involved a literature review; discussions with colleagues, practitioners, and family members; and discussions among NEILS investigators. The results of these efforts produced two outcome domains and eight evaluative questions (Bailey et al., 1998). Outcomes data will be gathered using the data sources already mentioned.

NEILS FAMILY OUTCOMES

FAMILY OUTCOMES	QUESTIONS
Family Perceptions of the Early Intervention Experience	1. Does the family see early intervention as appropriate in making a difference in their child's life? 2. Does the family see early intervention as appropriate in making a difference in their family's life? 3. Does the family have a positive view of professionals and the special service system?
Impact on the Family	1. Did early intervention enable the family to help their child grow, learn and develop? 2. Did early intervention enhance the family's perceived ability to work with professionals and advocate for services? 3. Did early intervention assist the family in building a strong support system? 4. Did early intervention help enhance an optimistic view of the future? 5. Did early intervention enhance the family's perceived quality of life?

Child outcomes will involve the domains of child functioning, quality of life, and service needs (Personal E-mail Communication, Kathy Hebbeler, NEILS coordinator, 4/17/98).

NEILS CHILD OUTCOMES

CHILD OUTCOMES	DATA SOURCE
Child Functioning Within Specific Developmental Domains	**Primary**
Quality of Life	Family telephone interview
Child Engagement (how child interacts with environment)	**Secondary**
Progress toward IFSP goals	Service provider report/survey
Service Needs At Ages 3 and 5	

It should be noted that the selection of child and family outcomes has not been finalized. It is estimated that NEILS will be completed in 2003.

EARLY CHILDHOOD RESEARCH INSTITUTE ON MEASURING GROWTH AND DEVELOPMENT (ECRI-MGD)

Status: In Progress

General Description

This study is funded by Early Education Programs for Children with Disabilities at the Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education. The goal of the measurement and growth project is to produce a comprehensive, individualized measurement system for children with disabilities from birth to eight years of age. The system will include the following: 1) indicators for monitoring progress and 2) solutions-oriented assessments to allow family and educators the opportunity to optimize child development outcomes.

Investigators from the Universities of Minnesota, Kansas, and Oregon are participating in the study. Five major products of the study include the following: 1) selection of general outcomes for children birth to age eight; 2) identification and evaluation of individual growth and development indicators; 3) development of exploring solutions assessments; 4) field testing and evaluations of "consumer satisfaction," and 5) dissemination (http://www.ici.coled. umn.edu8001/ecri, 2/2/98). To date, the institute has produced a draft report on the selection of general growth outcomes discussed below.

ECRI PROJECT STAFF

<table>
<tr><th>ECRI-MGD Investigators</th><th>ECRI-MGD Research Staff/Assistants</th></tr>
<tr><td>Center for Early Education and Development and Institute on Community Integration
University of Minnesota
Scott McConnell
Mary McEvoy</td><td rowspan="2">With assistance from:
University of Minnesota
James Ysseldyke

Parent Advocacy Coalition for Educational Rights (PACER)
Paula Goldberg</td></tr>
<tr><td>Juniper Gardens Children's Project, University of Kansas
Judith J. Carta
Charles R. Greenwood</td></tr>
<tr><td>Department of Applied Behavioral and Communication Sciences
University of Oregon
Ruth Kaminski
Roland H. Good III
Mark Shinn</td><td>Research Staff
University of Kansas
Jane Atwater, Dale Walker
Carol Leitschuh, Gayle Luze

University of Minnesota
Jeff Priest, Kristen Davis
Stephanie McNeill

University of Oregon
Deborah Laimon</td></tr>
</table>

Child and Family Outcomes

The focus of ECRI's first technical report is the selection of outcomes for children with disabilities from birth to eight. Family outcomes are beyond the purview of this technical report. Investigators approached the selection of child outcomes by seeking to validate outcomes after a "comprehensive review and synthesis of existing outcome statements" (Early Childhood Research Institute on Measuring Growth and Development, Draft Report, 1998). While the aim of the research team was to produce general outcomes for the age group of birth to eight years, they divided this age group into three subgroups: birth to two, three to five, and five to eight years. After developing specific outcome lists for each age group, these lists were then cross-referenced to produce a list of common outcomes for children aged birth to eight.

The research team formulated outcomes within the parameters of the social context within which they would be evaluated. These parameters included two main elements: 1) "the impact of outcomes on understanding and enhancing the development trajectories of young children with and without disabilities;" and 2) "how early childhood constituencies would perceive the appropriateness and usefulness of these outcomes" (Early Childhood Research Institute on Measuring Growth and Development, Draft Report, 1998). The investigators especially kept in mind the fact that "the future use of the general growth outcomes would hinge greatly on acceptance by families, teachers, administrators, and other individuals involved in early childhood education" (Early Childhood Research Institute on Measuring Growth and Development, Draft Report, 1998). The research team plans to submit the outcomes to early childhood constituencies for review.

(see ECRI Outcomes Table, Next Page)

The research team is in the process of testing various indicators and measuring processes for the above outcomes using a series of formative pilot studies employing different data collection formats such as naming pictures, playing with a peer, telling a story, as well as different scoring techniques. Investigators "expect to continue evaluating promising indicators empirically over the next two years, at least" (Personal E-mail Communication, Jeff Priest, ECRI research staff, 4/3/98).

The general aim of the project is to produce a set of outcomes for children and families with delaying or disabling conditions that can be monitored over time (specifically birth to age eight) and measured reliably. If the project is successful, it will address two of the most pressing problems in early childhood education research—measurement reliability and comprehensive outcomes conducive to longitudinal monitoring.

ECRI: CHILD OUTCOMES

OUTCOMES
The child uses language to convey and comprehend communicative and social intent
Child uses gestures, sounds, words, or sentences to initiate, respond to, or maintain word combinations.
Child uses gestures, sounds, words, or sentences to initiate, respond to, or maintain reciprocal interactions with others.
The child takes responsibility for their behavior, health, and well-being, even in the face of challenge or adversity
Child engages in a range of basic self-help skills, including but not limited to skills in dressing, eating, toileting/hygiene and safety/identification.
Child meets behavioral expectations (such as following directions, rules, and routines) in home, school, and community settings.
Child appropriately varies or continues behavior to achieve desired goals.
The child negotiates and manipulates the environment
Child moves in a fluent and coordinated manner to play and participate in home, school, and community settings.
Child manipulates toys, materials, and objects in a fluent and coordinated manner to play and participate in home, school, and community settings.
The child initiates, responds to, and maintains positive social relationships
Child interacts with peers and adults, maintaining social interactions and participating socially in home, school, and community settings.
Child appropriately solves problems in his/her interactions with others.
Child shows affect appropriate to the social context.
The child uses cognitive skills to explore the environment, reason, and solve problems
Child demonstrates an understanding of age-appropriate information.
Child demonstrates recall of verbal and non-verbal events.
Child understands and uses concepts related to early literacy and math skills.
Child solves problems that require reasoning about objects, concepts, situations, and people.

(Early Childhood Research Institute on Measuring Growth and Development, Draft Report, 1998)

CONSORTIUMS

Several federal projects have involved the compilation of results from individual state efforts to develop family and child outcome measures for children with disabling or delaying conditions. Two such consortiums will be discussed in this section. *By What Outcomes Should Part H Be Evaluated at the State Level?* is the result of the gathering of state Part H program evaluators invited by the Subcommittee on Service Integration and Continuity of Services of the Federal Interagency Coordinating Council to address the above question. *Longitudinal Studies of the Effects of Alternative Types of Early Intervention for Children with Disabilities: Follow-Up Institute* is the final report produced by the Early Intervention Research Institute (EIRI) regarding a federally-sponsored longitudinal project that took place from 1990-1995. Summary results will be presented, and individual state projects will be discussed in Chapter 4 (Development of Family and Child Outcomes at the State Level).

By What Outcomes Should Part H Be Evaluated at the State Level? May, 1997

General Description

The consortium focused on six main issues regarding the evaluation of Part H at the state level. These topics include the following: 1) service integration; 2) eligibility; 3) funding models and coordinating payment; 4) cost-effectiveness; 5) outcomes; and 6) measures. Since the focus of this chapter is on child and family outcomes, discussion will be restricted to the results regarding outcomes and measures.

Ten states participated in the conference. The production of the final report was funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services and written at the Early Intervention Research Institute at Utah State University. Participants were invited to two meetings in Washington D.C. (August and November 1996) by the Federal Interagency Coordinating Council to discuss the results of Part H evaluation efforts by individual states. Most of the individual projects were funded by state legislatures or Part H programs. As a result, some states emphasized implementation or funding issues more than child and family outcomes, depending on the interests and requirements of the funding agency. Through discussions of participants, however, focus questions involving all of the six areas emerged as well as general recommendations.

CONSORTIUM PARTICIPANTS AND OUTCOME STATUS

Participating States	State Representatives	Child Outcomes	Family Outcomes	Process Outcomes
California	Deborah Montgomery		X	X
Colorado	Heidi Phillips Shockley	X	X	X
Connecticut	Mary Beth Bruder	X	X	X
Florida	John Hall		X	X
Hawaii	Beppie Shapiro	X	X	X
Michigan	Charito Melesky Hulleza		X	X
New Jersey	Steven Barnett	X	X	X
North Carolina	Robin McWilliam		X	X
Pennysylvania	Jeffrey Brookfield			X
Utah	Richard Roberts, Mark Innocenti, Linda Goetz	X	X	X

Family and Child Outcomes and Measures

As the synthesis report states, "selection of specific outcomes is a difficult policy issue," especially given the fact that the sole focus of the consortium was how to evaluate Part H specifically. While some states assumed that Part H evaluation would involve child and family outcomes achieved as a result of early intervention, others did not and focused specifically on program implementation evaluation (Roberts et al., 1997).

States usually selected child and family outcomes with the counsel of experts, stakeholders, or both. A consensus of the consortium was that families and service providers should be involved in selecting the outcomes. With regard to measuring outcomes, it was noted that many outcome measures prevalent in early intervention evaluation cannot be reliably measured (see discussion in Chapter 7). Participants also stated that the nature of early intervention is to provide *individualized* services, which means that different outcomes may be used for measuring change in different children and families (Roberts et al., 1997).

Within these general observations and concerns, participants indicated that family involvement in, and family satisfaction with, the service system are potential outcomes. Ways of measuring these outcomes include ascertaining whether a parent feels control in selecting services. Another prevalent family outcome was family support—do families feel the service system provides them with the support needed to nurture their child? Participants did warn, however, that past research has indicated that parents tend to report high levels of satisfaction regardless of service provision quality (Roberts et al., 1997).

Other recommendations focused on a family's sense of improved quality of life as a function of receiving services. While quality of life is difficult to measure, participants suggested the following indicators: the ability of the family to participate in everyday community activities; adequate child care; parent ability to resume work; the increased manageability of child's needs; parent opportunity to engage in life activities; and parent opportunity to socialize (Roberts et al., 1997).

With regard to child outcomes, the consensus was that "developmental outcomes are important and Part H participation should afford positive effects in this domain." While a clear consensus did not arise, several general suggestions in this area were made. Participants felt that *specific* developmental outcomes should be measured, as well as other possibilities such as child engagement with the environment, child persistence, and child temperament. Participants also suggested parent-child interaction and general health outcomes such as a more positive home environment, lower risk status for abuse, appropriate immunizations, appropriate medical care, appropriate child care, and evidence of a medical home (Roberts et al., 1997).

Participants emphasized that a major factor in actually conducting studies which measure the above outcomes was cost:

> Most of the currently-funded evaluations use a mixed methodology that include interviews, questionnaires, and record reviews. Very few of the studies are conducting direct assessments of children and families and the direct measurement of program activities. The reasons these methods are not being used in more states are that direct assessment techniques are more expensive to implement (Roberts et al., 1997).

MOST FREQUENTLY USED DATA SOURCES

- interviews
- questionnaires
- record reviews

BY WHAT OUTCOMES SHOULD PART H BE EVALUATED: FAMILY OUTCOMES AND INDICATORS

FAMILY OUTCOMES	INDICATORS
⇒ Family Involvement in Services	parent feels control in selecting services
⇒ Family Satisfaction	parent feels control in selecting services
⇒ Family Support	parent feels service provides support
⇒ Improved Quality of Life	the ability of the family to participate in everyday community activities adequate child care parent ability to resume work the increased manageability of child's needs parent opportunity to engage in life activities parent opportunity to socialize

BY WHAT OUTCOMES SHOULD PART H BE EVALUATED: CHILD OUTCOMES AND INDICATORS

CHILD OUTCOMES	INDICATORS
⇒ Developmental Skills	unspecified
⇒ Child Engagement with the Environment	unspecified
⇒ Child Persistence	unspecified
⇒ Child Temperament	unspecified
⇒ Parent/Child Interaction	unspecified
⇒ General Health	more positive home environment lower risk status for abuse appropriate immunizations appropriate medical care appropriate child care evidence of a medical home

Some general concerns expressed regarding data collection methods mentioned in the table were: Likert scales of satisfaction are inadequate in examining satisfaction; there are issues with report reliability from parents/providers; pre-existing state data bases are often not consistent year-to-year and merit caution; and questionnaires whose distribution relied on community service providers were often given only to those favorably disposed to that service provider (Roberts et al., 1997).

General conclusions regarding outcomes and measures were as follows:

- Few outcome measures have been developed to the point where they could be used to assess the results of a comprehensive, coordinated system of services for families.
- Discovery of such outcomes is just beginning.
- Most current evaluation relies on implementation assessment.
- To what degree emphasis should be placed on particular development outcomes as opposed to well being, inclusion, and social adaptation is heavily debated.
- Measurement issues are very problematic so multiple measures should be used (Roberts et al., 1997).

EARLY INTERVENTION RESEARCH INSTITUTE (EIRI)
1986-1995

General Description

The Longitudinal Studies of the Effects of Alternative Types of Early Intervention for Children with Disabilities is a synthesis report of a series of longitudinal studies which took place from 1986-1995. The original project began enrolling subjects in sixteen different studies in October 1986. These sixteen studies collected data until the fall of 1990. Nine of the original sixteen studies conducted follow-up research from 1990-1995. This report summarizes findings for the nine studies followed longitudinally and includes data for the entire span of the projects, 1986-1995 (Innocenti, 1996). Only seven of these studies have been included in this discussion as two of the studies applied to preschool children rather than those aged birth to three.

The studies were funded by the U.S. Department of Education in order to evaluate the effects and costs of alternative types of early intervention programs for children with disabilities. The Department of Education sought to address three factors and concerns of the time (1985): 1) the limited high quality early intervention research for children with disabilities; 2) pressures to expand early intervention programs for children with disabilities; and 3) the almost total absence of efficacy research which included a cost-benefit analysis. As a result it was required that each study 1) be a true experiment (randomized controlled trial) in which two alternative types of intervention were compared; 2) consider the effects of the intervention on both children and families; 3) analyze the cost of the alternative types of intervention in conjunction with the effects; and 4) be carried out in field-based settings which were representative of the state-of-the-art early intervention programs. The three elements of early intervention to be examined were intensity, age at start of intervention, and program variation. The general aim of the

studies was to ascertain which elements of early intervention were working well and at what cost (Innocenti, 1996).

EIRI: PARTICIPATING SITES AND RESEARCH FOCUS

PARTICIPATING SITE	RESEARCH FOCUS
New Orleans, Louisiana	Intensity
Chicago, Illinois	Intensity
Bentonville and Fayetteville, Arkansas	Intensity
Salt Lake City, Utah	Age at Start
Charleston, South Carolina	Age at Start
Columbus, Ohio	Program Variation (coordinated versus traditional NICU transition services)
Des Moines, Iowa	Program Variation (parent involvement)

Child and Family Outcomes

The summary report emphasized that the selection of child and family outcomes was restricted because "the procedures for assessing child change attributable to intervention are inadequately developed, and totally satisfactory instruments are not available. With regard to measuring the impact of early intervention on families, the field is even less well developed." In response to concerns that early intervention research has been too narrowly focused on intelligence measures, other areas such as social-emotional growth, adaptive behavior, and elements of family functioning were included. Participants indicated that although it was desirable to include broader outcomes, lack of instrumentation and cost were factors (Innocenti, 1996).

Within this framework, all studies included the outcome domains of child and family functioning. Specific outcomes included the following: cognitive, motor and language skills; mother and child interaction; parental attitudes towards their child with a disability; special education placement and grade retention; and parent stress. Each participating study site had to include the core set of assessment instruments (listed in the table below), but could include other measures to suit specific needs.

EIRI: CHILD AND FAMILY OUTCOMES AND INSTRUMENTS

CHILD OUTCOMES	FAMILY OUTCOMES	INSTRUMENTS
• Social Skills • Adaptive Skills • Motor Skills • Communication Skills • Cognitive Skills • Broad Knowledge • Personal Living • Community Living • Independence • Problem Behaviors • Academic Competence • Child Health	• Adaptability • Cohesion • Social Support • Stress	CHILD Battelle Development Inventory Woodcock-Johnson Tests of Achievement Scales of Independent Behavior Social Skills Rating Scale Pictorial Scale of Perceived Competence and Acceptance FAMILY Parenting Stress Index Family Support Scale Family Resources Scale Family Inventory of Life Events and Changes Family Adaptation and Cohesion Evaluation Scale-III Child Health Additional Services Family Information Survey

While this report brought together a number of well-designed research projects, it should be noted that the results cannot be generalized to the national population. The participation of state sites was assessed on specified criteria, and the state sites themselves were not representative of statewide programs or children and families with disabling or delaying conditions.

SUMMARY

Review of the above projects presents several implications for the state of Washington. In selecting child and family outcomes for children with disabling or delaying conditions and their families several factors should be taken into account: 1) purpose of study; 2) type of information desired; 3) costs. Often factors one and two are influenced by factor three.

Purpose of Study

It is important to be able to specify precisely what information is desired. If a state wishes to examine directly early intervention impacts on children and families with individual observations or use standardized tests, then the cost rises. Most studies of this nature are

conducted by universities with federal grant money on samples of children with specific participation criteria. If the purpose of the study is changed to examining the perception of various participants regarding early intervention rather than attempting to directly measure outcomes, a state could use non-standardized instruments such as surveys. Given the measurement difficulties, inadequacies of standardized tests for the disabled and delayed condition population, the difficulty of selecting pertinent outcomes, and the costs, many states have chosen evaluation studies that do not assess directly child and family outcomes. While much state research activity does attempt to assess directly family and child outcomes, the purpose of such studies is usually not to assess early intervention broadly, but to examine a population affected by a specific condition (such as autism) or intervention feature (such as intensity).

Type of Information

If the type of information desired is to be obtained by non-standardized methods, outcomes should be stated to reflect the methodology. For instance, in the National Early Intervention Longitudinal Study (NEILS), where outcomes will be assessed primarily by surveys and interviews, outcomes were worded to reflect a subjective approach. For example, the outcome was stated, Did early intervention enhance the family's *perceived* quality of life? Rather than the more direct, Did early intervention enhance the family's quality of life?

If the study chooses standardized tests, gains in standardization may be diminished by lack of instrument sensitivity. As was mentioned in the Early Intervention Research Institute (EIRI) study, researchers were frustrated that many outcomes of interest, such as child-parent interaction and social skills, had few reliable instruments (especially for the disabled and delayed condition population). Scientific studies have often relied on measures of intelligence simply because the instruments are, for the most part, reliable. Researchers question, however, whether a small gain in IQ is as important an outcome as broader social ones, like, "the child is able to play appropriately with others."

The Early Childhood Research Institute on Measuring Growth and Development Study (ECRI-MGD) offers promise in regard to this dilemma. The selection of child outcomes acceptable to early intervention stakeholders that can be traced from birth to eight years and incorporate both technical skills and social ones is an encouraging development. The issue yet to be addressed is whether reliable objective measurement instruments can be developed for the outcomes. Individual national groups are also making efforts in this area. The American Speech-Language Association, for instance, is working on a National Outcomes Measurement System (NOMS) for speech-language pathology and audiology. The system is designed to develop a national outcomes database to demonstrate the value of speech-language pathology and audiology services. NOMS includes four components, each targeted to specific populations: birth to kindergarten; school-aged in education; school-aged in health care settings; and adults (Moore, 1998).

Costs

As described above in the review of the consortium on state efforts to evaluate Part H, most projects relied on information collected via surveys, record reviews, or questionnaires. Participants expressed that standardized tests are expensive, not standardized to children with disabling or delaying conditions, and in some cases not reliable measures of the outcome at hand, especially outcomes other than child intelligence. Non-standardized instruments can also be tailored to suit individual programs and information requirements. Such measures, however, have not been validated as extensively as many standardized tests and offer little objective assessment of family and child outcomes.

Another element of cost to consider is the number of study subjects needed in order to gain statistically significant results that can be generalized to the state population (of children with disabling or delaying conditions and their families). Usually these numbers are quite large, which increase research costs. As a result, often objective evaluation of family and child outcomes involves a smaller sample population that cannot be used to generalize the results statewide, but can draw some conclusions about early intervention for a specific population (e.g. autistic children) or program element (e.g. intensity).

Decision makers in Washington State, as other states, should take into consideration these factors when deliberating which type of study to conduct.

CHAPTER 4

DEVELOPMENT OF FAMILY AND CHILD OUTCOME MEASURES AT THE STATE LEVEL

INTRODUCTION

State activity takes place on several levels. Some state studies focus on Part H implementation; some focus on child/family outcomes research which sample from a defined locale within the state; and others examine study feasibility issues. Studies are usually conducted by state agencies, universities, independent research organizations, or programs themselves. This section describes various state research efforts which were presented at the National Early Childhood Technical Assistance System (NEC*TAS) Conference in 1997, at the Part H Consortium, or were part of the Early Intervention Research Institute study (see Chapter 3, Development of Family and Child Outcome Measures at the Federal Level, for descriptions). Only those directly relevant to child and family outcomes will be discussed in detail.

The following table summarizes the activity of those states which presented at the NEC*TAS conference. The three categories of study types are implementation, research, feasibility/exploratory. *Implementation studies* assess Part H and Part H programs. All include process outcomes, most include family outcomes, and some include child outcomes. *Research studies* assess the impact of a particular aspect of early intervention (such as program intensity) by examining selected child and family outcomes. *Feasibility/Exploratory studies* focus on investigating assessment options and gathering program information and participant input.

SUMMARY OF BIRTH TO THREE EARLY INTERVENTION STATE RESEARCH PROJECTS PRESENTED AT NEC*TAS

State	Type of Study	Child Outcomes	Family Outcomes	Process Outcomes
Arkansas	Research	X	X	
California	Implementation		X	X
Colorado	Implementation	X	X	X
Connecticut	Research	X	X	
Delaware	Research	X	X	
Florida	Implementation		X	X
Hawaii	Feasibility/ Exploratory	X	X	X
Illinois	Research	X	X	
Indiana	Feasibility/ Exploratory			
Louisiana	Research	X	X	
Michigan	Implementation		X	X
New Jersey	Implementation	X	X	X
North Carolina	Implementation			X
Ohio	Research	X	X	
South Carolina	Research	X	X	
Utah (2 studies)	Research Implementation	X X	X X	X

IMPLEMENTATION STUDIES

The goal of implementation studies is to assess Part H. All of these studies include process outcomes, most include family outcomes, and some include child outcomes. As the focus on this section is child and family outcomes, process measures will not be discussed. When reviewing child and family outcomes, it becomes necessary to discuss how the outcomes will be measured. The following table lists the child and family outcome measures, as well as the data source, selected by those states presenting at the NEC*TAS conference who were conducting implementation studies.

CHILD AND FAMILY OUTCOMES AND DATA SOURCES: IMPLEMENTATION STUDIES (NEC*TAS)

State	Child Outcomes	Family Outcomes	Data Sources
California		Family Satisfaction	Family Survey
Colorado	Infants Enhance Development	Parents Gain Support Families Understand Part H	Focus Groups With Parents Interviews With Providers Provider Survey Family Survey Community Self-assessment Record Reviews Site Visits
Florida		Perception of Effectiveness Parent Satisfaction	Family Written Survey Family Interview
Michigan		Increased Support Empowerment Stress	Part H Coordinator Survey Provider Survey Family Survey Site Visits
New Jersey	Child Development Child Behavior	Parenting Stress Mother/Child Interaction	Standardized Tests Records Review Family Interview Service Provider Survey
Utah	Child Development Transition Experience	Family Satisfaction Participation in IFSPs Transition Experience	Standardized Test Parent Interviews Teacher Interviews Family Questionnaires

The most common child outcome selected was child development. In the family outcome domain, parent satisfaction, support and empowerment outcomes were most frequent. Methods of data collection relied heavily on surveys and interviews. Standardized tests were used to measure general child development.

RESEARCH STUDIES

The following tables describe state projects that participated in the Federal Early Intervention Research Institute (EIRI) project from 1986-1995 (see Chapter 3, Development of Family and Child Outcome Measures at the Federal Level, for a description). All projects were randomized controlled studies in which two or more alternative types of intervention were compared.

EIRI STATE RESEARCH PROJECTS: TOPICS AND SUBJECT NUMBERS

LOCATION	STUDY TOPIC	NUMBER OF SUBJECTS
Arkansas (Bentonville and Fayetteville)	Standard intensity compared to two variations of intensity	78
Illinois (Chicago)	Once a week services compared to three times per week services	72
Iowa (Des Moines)	Classroom intervention with parent involvement compared to classroom intervention without	76
Louisiana (New Orleans)	Weekly, individual parent-child sessions compared to monthly parent group meetings	35
Ohio (Columbus)	Coordinated, comprehensive service for medically fragile infants prior to discharge compared to routine service	50
South Carolina (Charleston)	Compared 3 months adjusted age at start for medically fragile premature infants to 12 months adjusted age at start	68
Utah (Salt Lake City)	Compared 3 months age at start for medically fragile infants to 18 months age at start	60

Some outcomes were common to all states, and some were state specific. All of the research studies included the outcome domain of child development. Indicators of child development involve the following: Social Skills, Adaptive Skills, Motor Skills, Communication Skills, Cognitive Skills, Broad Knowledge, Personal Living, Community Living, and Independence.

Other child outcomes included in all the studies were Academic Competence and Child Health. Family outcomes which were included in all the studies were adaptability, cohesion, social support, and stress. All outcomes were measured by standardized tests. The following table displays those outcomes which each state additionally chose to add to the study designs.

EIRI: ADDITIONAL CHILD AND FAMILY OUTCOMES SELECTED BY PARTICIPATING STATES

Location	Child Outcomes	Family Outcomes	Data Sources
Arkansas	Child Self-concept	Parent Self-awareness Parent Participation Feedback About Intervention	Standardized Tests Questionnaire
Illinois	(Requirements Only)	(Requirements Only)	Standardized Tests
Iowa	(Requirements Only)	Knowledge of Parents	Standardized Test
Louisiana	(Requirements Only)	Mother/Child Interaction Parental Attitudes Towards Child	Standardized Tests
Ohio	Child Temperament	Parent Protective Behavior Parent Vulnerability	Standardized Tests
South Carolina	Child Self-concept	(Requirements Only)	Standardized Tests
Utah	Child Temperament	Parent/Child Interaction Parent Self-concept Parent Participation	Standardized Tests

The research studies used almost exclusively standardized tests and had small subject numbers. Results could not be generalized to the state's population of children with disabling or delaying conditions and their families because subject selection took place within a specific locality. The purpose of these studies was to assess the impact of certain elements of early intervention rather than generally assess early intervention in the state.

FEASIBILITY/EXPLORATORY STUDIES

Some states have chosen to conduct feasibility studies which assess methods for evaluating early intervention. As with other types of studies, feasibility projects can be either narrowly focused (e.g. How do we evaluate Part H implementation?) or more broadly construed (How do we evaluate early intervention services?). Exploratory studies often seek to gain understanding of program operations, ascertain perceptions of early intervention participants, or identify strengths and needs. The following is a description of each type of study conducted by two states participating in the NEC*TAS conference.

Feasibility—Hawaii

The University of Hawaii received funds from the Office of Special Education Programs, U.S. Department of Education to conduct two feasibility studies (1992-1995) which addressed the following questions:

1) How effective and efficient is the current early intervention system?
2) What outcomes are achieved by families through early intervention?
3) What outcomes are achieved by children through early intervention?

The discussion of the studies in this section will focus on child and family outcomes. Each of the studies was a two-year project. Data collection methods involved a literature review, key informant (parents, service providers, program coordinators, medical personnel) interviews and surveys, focus groups, site visits, records review, and checklists.

What Outcomes Are Achieved by Families Through Early Intervention?

The major finding of this study was the lack of information available in early intervention programs regarding identification of the needs (and strengths) of enrolled early intervention families in Hawaii. The research team first tried to identify family needs and how they were being addressed in order to assess what family outcomes should be. Since information regarding needs was lacking, the study concentrated on creating methodologies for collecting this information. As a result, recommendations regarding actual outcomes were limited by the fact that information on actual goals and objectives for families was not present. The study did recommend, however, two broad domains: empowerment and family functioning.

What Outcomes Are Achieved by Children Through Early Intervention?

The major recommendation of this study in regard to assessment was to conduct a series of small-scale evaluations which focused on the two child outcomes of life skills and school readiness. In terms of evaluation methods, the study concluded that "the only evaluations which seemed feasible were non-experimental designs without comparison groups." (Roberts, 1997). It was suggested that school readiness could be measured by asking kindergarten teachers to rate random samples of early intervention "graduates" and

compare them to those who had not received early intervention (Personal E-mail Communication, Beppie Shapiro, project coordinator, 4/6/98).

In summary, the research team concluded that "it is impossible at the moment to evaluate early intervention programs by measuring child developmental outcomes. The complexity of adjusting achieved developmental status, at say, three years, to account for the difference between expected gains given child diagnosis, type and degree of environmental risk, severity or degree of developmental problem, and maturity, is overwhelming. Since Part H is an entitlement, no comparison group can exist." (Personal E-mail Communication, Beppie Shapiro, project coordinator, 1/6/98). It was suggested that focusing on process measures (effectiveness of Child Find, timeliness of service, accomplishment of IFSP goals) was a more feasible approach to early intervention evaluation for Hawaii.

CHILD OUTCOME DOMAIN	FAMILY OUTCOME DOMAIN
Life Skills	Empowerment
School Readiness	Family Functioning

Exploratory Study—Indiana

The Center for Innovative Practices for Young Children, an affiliated program with Indiana University-Bloomington, is conducting a qualitative study examining Indiana's First Steps Early Intervention System (FSEIS) for the Bureau of Child Development in Indiana's Family and Social Services Administration. The purpose of the study is to accomplish the following:

1) to determine expressed purposes, goals, and guiding principles of FSEIS in order to determine a set of criteria for evaluating quality and impact of early intervention services;
2) to discover how services are carried out; determine the impact of FSEIS on children, families and communities as determined by early intervention stakeholders;
3) to determine perception of stakeholders with regard to program quality;
4) to determine needed resources and supports.

The study took place from 1995-1997 and the final report is pending at this time. In exploring the above issues the principal evaluators examined data from existing databases and other evaluation activities, conducted telephone interviews with stakeholders, conducted on-site interviews and observations, conducted family interviews, surveyed families statewide, and established a State Review Team (www.isdd.indiana.edu/fseval.html, 3/17/98). About 159 stakeholders participated from around the state (Personal E-mail Communication, Michael Conn-Powers, researcher, 4/7/98).

While the final report is pending, one major finding of the study was the "absence of clearly defined outcome-oriented goals among constituents." Participants emphasized process and service quality oriented goals. In regard to child outcomes, improvement in child development and the acquisition of major milestones were common themes. Researchers pointed out that selecting specific milestones and skills was problematic due to the diversity of needs and strengths in the early intervention population. It is under consideration to recommend an "exiting" measurement survey which would ask families what their goals were in this area and how well they accomplished them. (Personal E-mail Communication, Michael Conn-Powers, researcher, 4/7/98)

SUMMARY

In terms of the statewide evaluations discussed above, Child Development, Readiness to Learn, and Life Skills are common child outcomes. Such outcomes can be measured both through standardized tests, or non-standardized data collection methods (non-standardized surveys, interviews, questionnaires). Family Empowerment and Family Functioning are prevalent family outcome domains which can also be measured by standardized or non-standardized instruments. Indicators for these domains are quite varied and can depend on the data collection method and the focus of the study.

Evaluation of early intervention programs with regard to family and child outcomes is a complicated matter. Issues of cost, scientific validity, study designs and focus are a few common topics emerging from the summary of state activity by NEC*TAS, Early Intervention Research Institute study and Consortium participants. Some states have chosen to evaluate early intervention programs in terms of process measures. Some have chosen child and family outcomes that are suited to subjective evaluation (such as satisfaction or perceived impact); others have selected projects which use more objective means to measure outcomes and focus on specific aspects of early intervention programs. Others have conducted exploratory or feasibility studies to collect decision-making information. In choosing which studies to do, states should balance cost, scientific validity, desired information, and desired study focus in order to determine what is best suited to their particular circumstances.

CHAPTER 5

LOCAL ASSESSMENT IN WASHINGTON STATE

A number of communities and programs in Washington State have developed procedures for assessing local early intervention efforts. The *Local Assessment Survey* (Appendix D) was developed to identify program evaluation activities undertaken at the local level that might inform statewide evaluation activities. The survey was sent to child developmental programs, County Interagency Coordinating Councils, Educational Service Districts, Infant Toddler Early Intervention Program Lead Agencies and additional contractors, neurodevelopmental centers, school district Special Education Directors for schools who currently serve children, tribal authorities, University Affiliated Programs, and University Special Education Teacher Preparation Programs.

A total of 309 surveys were mailed. This included duplicate listings for organizations both within and between targeted mailing categories. With only a few exceptions, no attempt was made to contact non-responders after a single mailing. As this was intended to be a probe for information, responses were not anticipated from all those surveyed. Eighty-nine organizations responded, from programs within all of the categories listed above and associated with every county.

LOCAL ASSESSMENT ACTIVITIES

Responses from the *Local Assessment Survey* were focused into three categories: 1) *surveys* developed by an organization to provide specific feedback; 2) processes used to *track children's progress*; and 3) *tracking children's services after age three*.

Surveys

All programs that contract with the Infant Toddler Early Intervention Program receive its Self-Assessment Tool (Infant Toddler Early Intervention Program). This includes sample parent/family and provider surveys, used directly by some organizations. Other programs have developed their own surveys. Thirty-four Local Assessment Survey respondents indicated that they had developed their own survey(s) targeted at either families and/or staff. These respondents included County Interagency Coordinating Councils, developmental centers, neurodevelopmental centers, school districts, Infant Toddler Early Intervention Program contractors, tribal organizations, and University programs. The represented organizations reside in eighteen counties and are spread among counties which are metro (38%), small urban (35%) and rural (26%) in character.

Twenty-six respondents had developed parent/family surveys which addressed issues such as whether families perceived their needs as being met; program convenience, responsiveness, and/or sensitivity; coordination of services; family choice, awareness of options, and/or control; level of comfort with staff and/or program; knowledge gained; the referral experience; specific staff areas, Family Resources Coordinators; level of involvement or participation; and family support. Some surveys also discussed obstacles,

life improvements, and stress levels. An additional ten surveys were directed toward families but were more specific in nature, i.e., concerned with parent needs, health, interests, gross child development, the fit of the parent match (for parent support), transportation issues, or transitions.

Four respondents mentioned staff surveys. These included a self-assessment for "helping" parents (parents involved in parent support), a survey which addressed family support worker duties, and staff surveys concerned with transition.

Tracking progress

All programs track the individual progress of children through their Individualized Family Service Plans (IFSP). These plans outline service components and desired outcomes for children and their families, and are updated periodically to reflect new goals as development and needs are reassessed. While many respondents cited this process of tracking children's progress, thirteen respondents noted specific additional or related tracking activities. Represented organizations include developmental centers, neurodevelopmental centers, school districts, Infant Toddler Early Intervention Program contractors, tribal organizations, and University programs, and are located in twelve counties which are metro (27%), small urban (31%) and rural (42%) in character.

Of these organizations, almost half (six) noted the use of various curriculum-based assessment, evaluation, and programming systems, which track progress and help with individual goal-setting. Other responses included broad compilations of numbers served and exited, as well as more specific programs such as a monitoring program designed for high school parents and their children.

The Neurodevelopmental Centers of Washington have begun an additional tracking activity, partially supported by the Department of Health. Six neurodevelopmental centers are taking part in a one-year trial of WeeFIM, a functional improvement measurement tool for children from six months to seven years of age and older. This is the pediatric version of the adult Functional Improvement Indicator (FIM) for patients undergoing medical rehabilitation. As with FIM, a national database of subscribers' data allows users to compare their data with regional and national performance figures. Information collected includes patient demographic characteristics, medical diagnoses, impairment groups, lengths of inpatient stay, costs, and functional assessments (self-care, sphincter control, transfers, locomotion, communication, and social cognition) undertaken during admission, treatment, discharge, and follow-up. The Neurodevelopmental Centers are working with Uniform Data System for Medical Rehabilitation (developers of WeeFIM) to increase the sensitivity of WeeFIM for the birth to three population. At the end of the trial period (October 1998) the Neurodevelopmental Centers of Washington will evaluate the applicability and usefulness of WeeFIM.

Tracking services after age three

A number of school district programs which offer both birth to three early intervention services (Part H) and preschool services (Part B) pointed out that they track children who remain eligible until kindergarten. In addition, five organizations mentioned longer term tracking activities. Sedro-Woolley School District noted that through the Washington State Information Processing Cooperative, they are able to track special education children from eligibility to the time of exit. Bethel School District tracks those who transition into district services, and is exploring the possibility of tracking through grades three or four. Two tribal organizations (the Roger Saux Health Center of the Quinault Indian Nation and the Port Gamble S'Klallam Tribe) noted that they have computerized systems by which they track their children, and this continues after age three. The Little Red School House, a developmental center with sites in Lynnwood and Everett currently serving approximately 130 children, is beginning to survey its graduates in order to gain insights into families' early intervention experiences and to track later placement and quality of life. They plan to routinely track new graduates at preschool entry and at the start of kindergarten, with more random sampling at later points in time.

RESEARCH STUDIES

Several more extensive research studies related to early intervention for infants and toddlers, birth to three, were identified within Washington State.

Washington Research Institute

Supporting Neurobehavioral Organizational Development in Infants with Disabilities: The Neurobehavioral Curriculum for Early Intervention. Rodd Hedlund, Principal Investigator, Washington Research Institute. The purpose of this project is the development, field-testing, and evaluation of a neurobehavioral curriculum for infants born with very low birthweight and their parents. The model assists early intervention professionals to: 1) observe and interpret the behavioral cues expressed by the infant; 2) learn and implement specific neurobehavioral strategies that support the infant's neurobehavioral organization and self-regulatory competence; and 3) support parents as well as paraprofessionals to recognize and support the neurobehavioral needs of these fragile infants.

A comprehensive evaluation of the Neurobehavioral Curriculum for Early Intervention (NCEI) was conducted for formative and summative purposes using both quantitative and qualitative procedures to capture the impact of the curriculum on a variety of indices including standardized measures of infant development, subtle changes in infant behaviors, and subjective impressions and feelings of care givers and early intervention professionals and paraprofessionals. Fifteen early intervention professional and paraprofessionals from three sites (Tacoma Learning Center, Valley Learning Center, and the Hospital to Home Program) participated in the field-testing and evaluation of the NCEI. Data were collected on a total of 48 infants (26 male and 22 female) and their families. To be included in the project, infants had to be chronologically or developmentally six months of age or younger. The infants' average chronological age was 11 months, ranging from 2.5

to 31 months. Average corrected age was 9 months, ranging from birth to 27 months. The infants' average gestational age was 33.5 weeks and their average birth weight was 2062 grams (~4.5 lbs). Forty of these infants had three or more significant medical conditions such as prematurity and very low birthweight (<1500 grams, 3.3 lbs), broncho-pulmonary dysplasia, developmental delays and vision or hearing impairments.

Results

The field testing and evaluation focused on five main areas: impact of the curriculum, impact of training, fidelity of implementation, formative evaluation of materials, user satisfaction, and cost-effectiveness.

Infant progress and caregiver-infant interactions

Pre- and post-test data were collected on infants' progress using the *Bayley Scales of Infant Development* and the *Early Intervention Developmental Profile*. On the Bayley Scales, significant gains ($p < .05$) were found for both mental and the psychomotor age equivalencies. On the EIDP, significant gains ($p<.05$) were found for age equivalencies in all six domains, Cognitive, Gross Motor, Communication, Fine Motor, Self-help, and Social. Data on infants' progress on *IFSP goals and objectives* (outcomes) and degrees and amount of *neurobehavioral supports* were collected on a quarterly basis. Over a six month intervention period, infants' progress on IFSP goals was significant for all six developmental domains. Decreases over time in degree and amount of neurobehavioral facilitation were also significant for cognitive, gross motor, communication, and fine motor goals.

Overall these results show that infants made significant progress on their IFSP *goals and objectives* (outcomes) as well as decreased their need for neurobehavioral facilitation.

Significant improvement in neurobehavioral organization was also found using the *Infant Behavioral Assessment (IBA)*, reflecting greater infant competence and reduced stress during interactions.

Qualitative information gathered from the early interventionists through questionnaires, informal interviews, and direct observations confirmed that interventionists found the NCEI strategies very helpful in improving infants' neurobehavioral organization and had an impact on infants' gains on their IFSP goals (outcomes).

Interventionists also found that as a result of their use of the NCEI strategies and parent materials, caregivers appeared more comfortable in a number of ways with their infants.

Impact of training, fidelity of implementation and formative evaluation of materials

Overall, trainees found the IBA and NCEI training very effective in increasing their knowledge on infant neurobehavioral organization, their ability to interpret infants' cues and provide neurobehavioral support to infants and families. Most interventionists

implemented the NCEI with all or most of the infants and families in their case load, including older children who were functioning at a low level.

The NCEI and the parent materials were found to be well thought out and organized. The neurobehavioral strategies and activities were comprehensive and easily understood. The parent materials were found to be positively worded, and understandable for average level readers.

User satisfaction and cost effectiveness

Overall, interventionists expressed satisfaction with most of the strategies and materials, and felt that parents also generally liked the strategies and materials. Most interventionists thought the strategies and parent materials were very easy to integrate within daily activities, and that they were very reasonable in terms of time and effort for preparation and implementation.

University of Washington

The Early Child Care Study of Children with Special Needs. Cathryn Booth, Principal Investigator, and Jean Kelly, Co-Principal Investigator. This longitudinal, ecological study is being conducted through the Department of Family and Child Nursing at the University of Washington. This project is designed to evaluate the effects of child care on the development of young children with special needs. The sample (n=160) includes those with diagnosed disabilities or delays (n=80) and those at risk for developing a delay (n=80) due to prematurity, respiratory distress syndrome, maternal abuse of drugs or alcohol, or other specified factors.

A longitudinal design is being used to evaluate child outcomes at 30 and 45 months as a function of the complex interactions among child characteristics, family characteristics, and the quality and type of home, early intervention, and child care environments in which the children develop. Children and their families participating in the study are being assessed at child ages 12, 15, 30 and 45 months. Interviews, questionnaires, structured and unstructured observations occur at home, at child care, and in the laboratory setting.

Families were recruited when the children were 12 months of age and are being followed through 45 months. A grant has been submitted to follow the children through second grade, in order to look at transition, inclusion and school-age outcomes.

Training and Early Intervention to Promote Quality Parent-Child Interaction in Homeless Families. Jean Kelly, Principal Investigator. This study is being conducted through the Department of Family and Child Nursing at the University of Washington.

Background and Purpose of Research

This project will provide early intervention services to homeless families being served by the YWCA, and train YWCA staff to provide the intervention services after the project is completed. One of the terrible aspects of family homelessness is a dramatically increased

risk that homeless children will be impaired both psychologically and cognitively, with immediate and long-term consequences for these children and society. The focus of this intervention will be to facilitate nurturing interactions between homeless parents and their children, birth to three years of age, in order to mitigate the children's risk for psychological problems and delayed development. The specific objectives of the study are:

1. To provide **training** to Greater Seattle YWCA program sites serving homeless families on how to provide one-on-one early intervention to facilitate healthy parent-child interactions.

2. To provide **direct early intervention** with parents and their young children, birth to three years of age, who are in YWCA transitional housing. The early intervention sessions will be the basis of the training. The intervention is designed to increase the quality of parent-child interactions.

3. To **evaluate** the project to determine changes in (a) the quality of interaction between participating parents and children and (b) YWCA parent educators' knowledge, performance, and satisfaction.

Evaluation

The pre- and post-assessments of staff (videotaped sessions of educators with parent-child dyads and knowledge and satisfaction questionnaires), and the parent-child interactions (videotaped sessions) will be used to evaluate the success of this training and early intervention project. Coders, blind to the design of the project, will code the videotapes of the parent-child play and teaching episodes, and the videotapes of the parent-educator sessions. The parent-child interactions will be coded using the Nursing Child Assessment Teaching Scale (NCATS) (Barnard, 1994). The parent-educator interactions will be coded using a coding scheme developed for the purposes of the study. Additionally, the parent-educator will complete The Competency Rating Scale (adapted from Leitch, 1995) used to rate knowledge and skill in each of the following areas: knowledge of infant/toddler states, behaviors and cues, parent-child interaction, providing feedback to parents during interactions, and establishing helping adult relationships in the early intervention settings, and a staff satisfaction questionnaire.

Parent-Child Communication Coaching. Kathryn Barnard, Principal Investigator, Susan Spieker and Colleen Morisset Huebner, Co-Investigators. This study, which is part of a national consortium of 15 projects evaluating the Early Head Start program, is being conducted through the University of Washington, School of Nursing, in collaboration with Families First Early Head Start program of the Children's Home Society of South King County. This project is designed to measure outcomes of an intervention known as Parent-Child Communication Coaching, whose intent is to facilitate the parent-child interaction in a positive manner and to facilitate the child's secure attachment to the parent, thereby boosting the child's cognitive and language development and preventing learning and emotional problems.

Two hundred families enrolled in the Families First program will be studied. One hundred of the families will receive the intervention, and 100 will serve as a control group. The core service of the intervention is a home visiting program. The Parent-Child Communication Coaching begins in pregnancy and continues with age specific interventions through the second year.

The broader Early Head Start program goals, which each have specific outcomes, include:

1. Enhance child development and social competence by promoting the child's development and supporting the provision of developmentally enriching caregiving and environments in the family's home and, when appropriate, the child care center.

2. Support family development and promote long term self-sufficiency and capability of parents.

3. Create stronger, responsive communities that share responsibility for the healthy development of children.

4. Recruit, develop and retain high quality staff.

Snohomish County

Snohomish County and the Region III office of the Division of Developmental Disabilities recently worked with consultant Susan Janko, Ph.D., University of Washington College of Education, to conduct a review of birth to three services for children with disabilities in Snohomish County. A community steering committee including families, educators, and service providers helped direct and advise the study.

Data were collected through the use of interviews, observations, and review of program documents. Interviews were conducted with families of children currently *using* birth to three services, families of children who had *previously used* birth to three services, families of children who were *eligible for but did not use* birth to three services, and representatives of programs providing services in Snohomish County. Observations were related to program sites and community information.

The review addressed five goals: 1) identify successful models of service; 2) learn about family preferences; 3) describe changes in children's and family's priorities and needs; 4) guide and support new options in response to families' priorities; and 5) develop ways to evaluate accomplishments and progress in the future. The final report, expected to be available in July 1998, will include recommendations regarding future directions for Snohomish County birth to three services.

CHAPTER 6

DATA INVENTORY

A wealth of information is available in secondary data sources on children in the state of Washington. An inventory of relevant technical data was conducted to identify possible indicators for child and family early intervention outcomes, and to assess the feasibility of obtaining access to these data.

Extensive information on children with special needs over the age of three is maintained in local school records. While school records are not readily accessible for research, both the Department of Health and Department of Social and Health Services (DSHS), Division of Developmental Disabilities maintain information for children to whom they provide services. Another source of information for children who are born to Washington residents is contained in the First Steps Database. Additional databases include that maintained by the DSHS, Children's Administration on child abuse, neglect and out-of-home placement. All of these databases can be linked to provide information on the background characteristics of children served, the type of services received, and some limited information relative to type of disability and outcome. Despite the plenitude of data, these secondary sources provide very limited information regarding child's disability and the family environment. As a result of the limitations in these secondary data sources, all of the proposed research projects using these secondary sources involve additional primary data collection.

DATA FROM OFFICE OF SUPERINTENDENT OF PUBLIC INSTRUCTION/STUDENT FILES

The confidentiality issues surrounding access to student identified data are significant. The release of personally identifiable information (without parental consent) is permitted in limited cases: in order to meet the requirements imposed by chapter 392-172 WAC; or to officials of participating agencies under the rules governing the Family Educational Rights and Privacy Act of 1974. In general, for written informed consent not to be required, the disclosure must be on behalf of school districts' efforts to improve instruction and the manner in which the information will be used to improve instruction must be clearly articulated. Permission to obtain an enrollment count for three to six year olds must be negotiated with Office of Superintendent of Public Instruction (OSPI) and would require Human Research Review Board (HRRB) approval. Permission for access to children's school records would have to be negotiated separately with each district or through written parental consent. With parental consent, HRRB approval, and support from OSPI it would be possible to review student files. Some of the information which would be contained in these student files is listed in Table 1.

DATA FROM DIVISION OF DEVELOPMENTAL DISABILITIES FILES

The Division of Developmental Disabilities maintains information in two major databases, the Common Client Database (CCD) and Trends and Patterns Database (TPD). These databases contain information on child development services, eligibility for services and family support services including respite care, attendant care, and nursing care. Information is collected on where the services are delivered, where the child resides, and the type of residence. The eligibility file contains information on type of disability. While CCD does not retain that information historically, TPD contains snapshots on that field indicating changes in the child's eligibility over time. One caution in interpreting the service delivery data is that information reported by month tracks authorization and payment through SSPS rather than receipt of services. A day program file contains information on date placed and date where involvement in the day (child development) program ended. Some of the information in Division of Developmental Disabilities database files in listed in Table 2.

DATA FROM DEPARTMENT OF HEALTH FILES

The Department of Health maintains information from local health jurisdictions in the Child Health Intake Form (CHIF) Automated System. This system contains background information on the child and their diagnostic category, but it does not appear to track the number and type of services delivered or other variables which might be useful for an outcome based evaluation. Six neurodevelopmental centers are using the Wee Functional Indicator Measure (WeeFIM) to track outcomes, and additional centers may use it in the future. This is a potentially rich source of information.

FIRST STEPS DATABASE

The First Steps Database contains information on all children born to Washington residents starting in July 1988. It is updated on an annual basis and it takes about a year before the births from a given year are added to the database. It currently contains births through December 1996.

The First Steps Database was established to track maternity care and birth outcomes for low income women who received prenatal care through Medicaid and other state supported programs. It originally contained information from birth certificates, linked Medicaid claims for the prenatal period and the year postpartum, and information on infant deaths. Its purposes have expanded and now it is routinely linked to data systems developed by the Children's Administration for tracking referrals for child abuse or neglect and for out-of-home placements and until 1996 it was annually linked to the substance abuse treatment encounter database (TARGET) maintained by the Division of Alcohol and Substance Abuse. In addition, information on child deaths through age six and enrollment in early intervention services have been linked to the First Steps Database for special projects.

Selected information which is already in or linked to the First Steps Database for all children born to Washington residents is listed in Table 3. For children whose mothers

had maternity care provided by the Medical Assistance Administration, additional information is available using these claims. The additional information available using claims is listed in Table 4. Other data elements which could be added to the First Steps Database by linking to other state data systems are listed in Table 5.

Six counts of children enrolled in early intervention services for children under three years old have been conducted by Research and Data Analysis (RDA) and were funded by the Infant Toddler Early Intervention Program (ITEIP). Most of the analyses which RDA has been able to perform depend upon linking the enrollment data to the First Steps Database. Approximately 15 percent of children enrolled in early intervention services were not born to Washington residents and are not in the First Steps Database. However, RDA projects could link those children to the data systems with information on child abuse and neglect, out-of-home placement and child and infant death. It is possible also to link those children to eligibility files in order to determine if they were covered by Medicaid. The limited information available on children not born to Washington residents is listed in Table 6.

TABLE 1. DATA FROM SCHOOL DISTRICT STUDENT FILES

Data	Availability	Notes
Enrollment in special education, Participation in inclusive settings	Yes	The files contain information on enrollment in special education, receipt of special services, and proportion of time in inclusive settings.
Child functioning	IFSP*	Collected at the individual level by school districts for children birth to three with Family Resource Coordinators (FRCs).
Severity of disability	IEP**	Individual evaluation for all children with disabilities in student files is conducted at the time of eligibility determination. Individualized Education Program contains information on proposed services, goals, and placement decisions.

*Individualized Family Service Plan
**Individualized Education Program

TABLE 2. DATA FROM DIVISION OF DEVELOPMENTAL DISABILITIES

Data	Source	Notes
Transitioning out of services	CCDB*	The eligibility file contains information on whether or not a child still qualified for/needed services which can be combined with the information on disability type. Information on disability type is kept historically in the Trends and Patterns Database.
Child residence	CCDB*	The residential file contains historical information on the type of residence of the child (institution, in-home, foster care etc.).

*Common Client Database

TABLE 3. DATA FOR CHILDREN BORN TO WASHINGTON RESIDENTS IN (OR ALREADY LINKED TO) THE FIRST STEPS DATABASE

BACKGROUND VARIABLES	SOURCE	NOTES
Mother's marital status	FSDB*	from birth certificate—at time of birth
Mother's age	FSDB*	from birth certificate—at time of birth
Mother's education	FSDB*	from birth certificate—from 1992 on
Eligibility for Medicaid	FSDB*	from OFM eligibility file—from conception through 2 years after
Ethnicity	FSDB*	from birth certificate—as stated on birth certificate
Receipt of prenatal pare	FSDB*	from birth certificate—month began prenatal care
Parity	FSDB*	from birth certificate—number of prior pregnancies or prior children
Amniocentesis	FSDB*	from birth certificate
Birthweight	FSDB*	from birth certificate—grams
Gestational age	FSDB*	from birth certificate—estimated gestational age
Apgar score	FSDB*	from birth certificate
Enrollment in the Infant Toddler Early Intervention Program	RDA**	enrollment in B-3 on Dec '93, May '95, Dec '95, May '96, Dec '96, Dec '97
Condition: identified at birth	FSDB*	from birth certificate for conditions identified at birth
DATA	**SOURCE**	**NOTES**
Infant death	FSDB*	from matched infant death file for 7/88-12/95
Child death	FSDB*	currently linked for child deaths prior to 1996 for children born 7/91-12/94.
Accepted referral to child and protective services	CAMIS***	for children born after July 1, 1991; CAMIS data linked to FSDB for referrals through August, 1996 to children born before 1996
Placement by children's services out-of-home	CAMIS***	for children born after July 1, 1991; CAMIS data linked to FSDB for placements through August 1996 to children born before 1996

*First Steps Database
**Research and Data Analysis
***Case and Management Information System

TABLE 4. ADDITIONAL DATA FOR CHILDREN WITH MEDICAID ELIGIBILITY BORN TO WASHINGTON RESIDENTS, 7/1/1988-12/1/1996

BACKGROUND VARIABLES	SOURCE	NOTES
Maternal amniocentesis, CVS**	FSDB*	from Medicaid claims
Maternal substance abuse diagnoses	FSDB*	from Medicaid claims for women with Medicaid eligibility
Condition for Medicaid children	FSDB*	from Medicaid claims for children with Medicaid eligibility for the first 2 years of life
Medicaid/SSI*** eligibility	FSDB*	from OFM eligibility file—for kids for first 2 years of life—could be obtained for more years
Medicaid costs	FSDB*	from Medicaid claims—for non-Healthy Options kids

*First Steps Database
**Chorionic Villa Sampling
***Supplemental Security Income

TABLE 5. DATA WHICH COULD BE OBTAINED AND LINKED TO THE FIRST STEPS DATABASE FOR CHILDREN OF WASHINGTON RESIDENTS

BACKGROUND VARIABLES	SOURCE	NOTES
Employment data	ESD*	Quarterly wage data for mother and father (if listed on birth certificate)
Child's residence	OFM**	For children with Medicaid eligibility, most recent address could be obtained for last period of eligibility.
Mother's residence	DOL***	Mother's driver's license information to confirm current Washington residency and local school district
Medicaid diagnoses > 2 years	MAA+	Medicaid claims could be obtained for children over two years old to flag children with later diagnosed conditions
School district	FSDB-GIS++	Birth certificate address used to identify school district.

*Employment Security Department
**Office of Financial Management
***Department of Licensing
+Medical Assistance Administration
++First Steps Database-Geographical Information System

DATA	SOURCE	NOTES
Divorce/Marriage	DOH-CHS*	Information on divorces and marriages
Medicaid/SSI** eligibility	OFM***	For children who have any Medicaid eligibility, their continuance on Medicaid can be determined.

*Department of Health—Center for Health Statistics
**Supplemental Security Income
***Office of Financial Management

TABLE 6. DATA FOR ALL CHILDREN IN WASHINGTON STATE ENROLLED IN EARLY INTERVENTION SERVICES ON: 12/1993, 5/1995, 12/1995, 5/1996, 12/1996, AND 12/1997

Data	Source	Notes
Accepted referral to child and protective services	CAMIS*	for children born after July 1, 1991
Placement by children's services out-of-home	CAMIS*	for children born after July 1, 1991
Infant or child death	DOH-CHS**	currently linked for child deaths prior to 1996 for children born 7/91-12/94
Medicaid/SSI+ eligibility	OFM***	Children can be linked to the OFM files to determine Medicaid eligibility, including children not born to Washington residents.

*Case and Management Information System
** Department of Health—Center for Health Statistics
***Office of Financial Management
+Supplemental Security Income

CHAPTER 7

STUDY DESIGNS

This chapter presents possible options for study designs for evaluating the impact of early intervention on infants and toddlers, birth to three, with disabling or delaying conditions and their families in Washington State. Following a brief literature review, each study is described in full. Each study design includes the following: a description of the methodology, suggestions for child and family outcomes, suggested analysis techniques, a discussion of strengths and weaknesses, and estimated duration and costs of the study.

GENERAL LITERATURE REVIEW

The literature regarding the effectiveness of early intervention for children with disabling or delaying conditions and their families should be reviewed within the context of the field of child development itself. One impetus behind early intervention legislation was the emergence of data and developmental theories that indicated the unique intervention potential during the first few years of life (Futterweit and Ruff, 1993). As was previously discussed, development of neural synapses which form patterns of behavior and learning style occurs as early as infancy (Huttenlocher, 1990). Three populations of children are the targets of early intervention services: 1) those with established developmental delays or disabilities; 2) those at biomedical risk (such as low birth weight), and 3) those at environmental risk (such as those existing in poverty) (Tjossem, 1976). One of the aims of early intervention is to maximize each child's developmental potential. While it is generally accepted that early intervention is effective in stimulating development (Casto and Mastropieri, 1986; Guralnick, 1998), understanding the relationship between child and family factors, program factors, and types of outcomes desired is still being researched (Guralnick, 1998).

The questions of early intervention research—for whom does early intervention work, under what conditions, and toward what goals (Guralnick, 1988)—are shaped within the evolution of the field of child development itself. Early studies assessing intervention effects defined development as a strictly cognitive construct, more specifically, psychometrically defined intelligence (Guralnick, 1998). Current studies reflect trends in the field of child development which suggest that development should be construed in a much broader sense to include an array of social factors (Guralnick, 1997; Roberts et al., 1997). Similarly, earlier studies focused on child development as the sole outcome of intervention (Innocenti, 1996), while contemporary thought suggests that development is an interactive activity and emphasizes the importance of the family and social environment (Boyce, 1993; Casto and White, 1993; Crowley and Taylor, 1993:4; Gallagher, 1996). With the growth in emphasis on family focused early intervention strategies, recent studies have incorporated family outcomes as an integral part of intervention assessment (Bailey et al., 1998; Caro and Derevensky, 1991; Innocenti, 1996). As concepts of development and strategies of intervention evolve, the parameters of research change. It is within this context that a brief, general review of the literature will be presented. The individual

discussion of study designs contains a literature review section which elaborates on studies of that specific nature.

First Generation Research

Early intervention research is often categorized into two time periods. First generation research indicates research occurring from the early 60s until the late 80s; second generation research indicates research from the late 80s until the present.

The focus of first generation research has primarily addressed the issue of the general effectiveness of early intervention services. Many first generation studies have used at risk or economically disadvantaged populations to draw conclusions about the impact of early intervention programs (Casto and Mastropieri, 1986). These studies produced strong evidence that early intervention programs had a positive impact (Innocenti, 1996). Their results were supported by longitudinal studies which confirmed early intervention effectiveness in the long term such as the following: the Consortium for Longitudinal Studies (Lazar and Darington, 1982), the Perry Preschool Project (Berrueta-Clement et al., 1984), and the Abecedarian Project (Ramey and Haskins, 1981). Some researchers have questioned whether the results from studies using at risk, preschool aged children can be applied to those children, birth to three, with established disabling or delaying conditions (White and Casto, 1985). Despite these concerns, studies that did focus on birth to three populations of disabling or delaying conditions generally showed positive results (Guralnick and Bennet, 1987; Lovaas, 1987; McEachlin et al., 1993). Below are listed results from some reviews of first generation research pertaining to those with disabling or delaying conditions.

- In a review of 42 first generation projects researching the impact of early intervention services on the disabled population, Farran (1990) stated that there were short and long term gains in all areas of child development.

- In a review of 74 studies reviewing the impact of early intervention on children with disabling conditions, Casto and Mastopieri (1986) reported that participants in early intervention services experienced improvement in IQ, motor, and language skills.

- In a review of 21 demonstration studies for infants and children with Down Syndrome, Gibson and Harris (1988) noted that early intervention services had a positive impact on fine motor skills, IQs, and social behavior.

- In a review of 11 studies researching the impact of early infant stimulation programs on infants and children with Down Syndrome, Gibson and Fields (1984) reported gains in developmental skills and social habits.

- In a review of 74 studies for children with disabling conditions, Casto (1986) stated that "early intervention programs result in moderately large immediate benefits" in outcomes such as cognitive, language, motor, and social skills, and parent-child interaction.

- White, et al. (1985) conducted a review of the reviewers of first generation (until 1985) studies and reported that 94% of 52 primary literature reviewers concluded that early intervention services resulted in "substantial immediate benefits for handicapped, at risk, and disadvantaged populations."

First generation research faced a host of methodological problems which include the following: 1) lack of random assignment, 2) subject selection, and 3) problems of measurement (Bricker et al., 1984; Farran, 1990; Guralnick, 1991). Second generation research faces similar difficulties. These problems will be discussed in the subsequent section, Methodological Challenges. While these methodological problems have affected a large number of studies (Casto and Mastropieri, 1986; Shonkoff and Hauser-Cram, 1987), it is generally accepted that early intervention has a positive impact for children with disabling or delaying conditions (Casto and Mastropieri, 1986; Guralnick 1997; Shonkoff and Hauser-Cram, 1987), and that first generation research has "put the global question about whether or not early intervention is effective to rest" (Guralnick, 1997).

Second Generation Research

Second generation research attempts to respond to the shortcomings of first generation research and incorporates current developments in the field of early childhood development. First generation research measured the effectiveness of early intervention programs from the early 60s to the late 80s. Programs at this time were newly developed, uncoordinated and fragmented (Guralnick, 1997). As a result, *which* element of early intervention was effective (or not) was not often discernible in earlier studies. Earlier studies also failed to take into account established independent variables that may affect the developmental progress of a child and family. Without taking these into account, conclusions regarding the impact of early intervention may be erroneous (Shonkoff et al., 1988). As a result, second generation research has focused on ascertaining which elements of early intervention have a positive impact on which type of subjects under what circumstances. A typical study of this type is *Longitudinal Studies of the Effects of Alternative Types of Early Intervention for Children with Disabilities* (Innocenti, 1996).

While first generation research focused primarily on cognitive child development, the concept of development has been widened to include skills that will allow children to participate in valued roles in the community, perform to the best of their ability in school and be able to become contributing members of society. To assess these goals, outcomes other than IQ, such as adaptive, communication, and social skills have become prevalent (Casto and Lewis, 1984; Guralnick, 1991 and 1989; Hauser-Cram and Shonkoff, 1988).

The growing emphasis on the importance of the effect of family and social environment on a child's development has expanded the concept of development even further. While previous studies focused solely on child outcomes, current research has begun to discuss and assess impact of early intervention on families especially in the areas of family support, parent-child interaction, family empowerment, and knowledge needed to enhance a child's potential for development (Boyce, 1993; Casto and White, 1993; Cleary, 1988; Crowley and Taylor, 1993:4; Gallagher, 1996, Kelly and Barnard, in press).

In sum, second generation research has moved beyond the general impact question and attempts to identify the "child characteristics, family characteristics, and program features that interact to optimize one or more outcomes within the framework of contemporary early intervention services" (Guralnick, 1993).

Some General Results of Second Generation Research

Some general results of second generation research are listed below. These conclusions were drawn by the referenced authors after a review of second generation studies. The projects were randomized controlled studies or met the criterion of "believability" which McLean and Cripe (1997) describe as requiring that a "skeptical reviewer would believe that the study's results were almost certainly attributable to the experimental intervention, and not to maturation or some other uncontrolled variable" (McLean and Cripe, 1997).

- Early intervention is effective in training mothers to be more responsive to infants with developmental delays (Spiker and Hopmann, 1997).
- Infant stimulation had a positive impact on motor skills for children with cerebral palsy or related motor delays, especially when parent mediated (Harris, 1997).
- Therapeutic treatment for young children (birth to four years) with cerebral palsy or motor delays has a greater impact on development than for older (four to eight years) children with cerebral palsy or related motor delays (Harris, 1997).
- Parent understanding of and compliance with therapeutic intervention programs positively affect the development of fine motor skills of children with cerebral palsy and motor disabilities (Harris, 1997).
- Early intervention programs using the Mother-Infant Communication Program[1] positively affect maternal responsivity to children with communication disorders (McLean and Cripe, 1997).
- Families using Hanen Early Language Parent Program[2] increased the frequency and duration of joint and interactive engagement with their children diagnosed with communication delays than families who did not use this model (McLean and Cripe, 1997).
- More successful treatment with greater efficiency has occurred when children with communication disorders are enrolled in early intervention at a young age (McLean and Cripe, 1997).
- Parents can serve as effective interventionist for children with communication disorders (McLean and Cripe, 1997).

---

[1] This program emphasizes strengths of mothers by focusing on behaviors already being used in order to increase maternal responsivity to children with communication delays. It incorporates nondirective strategies such as modeling, video feedback, and planned practice (McLean and Cripe, 1997).

- Children with communication disorders functioning at levels of prelanguage and early language development respond more positively to treatment which is highly systematic and takes place in naturalistic[3] settings (McLean and Cripe, 1997).
- Early intervention has been effective in teaching children with autism to pay attention to other people, to imitate others, to comprehend and use language, to play appropriately with toys, and to interact socially with others (Dawson and Osterling, 1997).
- Children with autism demonstrate greater improvement in developmental areas when parents are included in the child's intervention service (Dawson and Osterling, 1997).
- Children with autism respond positively to highly structured, low staff-child ratio programs (Dawson and Osterling, 1997).
- Children with autism require more intensive intervention than other conditions to achieve positive results (Dawson and Osterling, 1997).

These findings are by no means comprehensive, but they do demonstrate the focus of contemporary research. Rather than assess general impact of early intervention, second generation studies address questions regarding the influence of specific program features and curricula (such as Hanen Early Language Parent Program, or structured versus less structured), child characteristics (such as type of condition), and family characteristics (such as parent-child interaction). Second generation research aims to be more methodologically sound than previously; however, inherent difficulties remain.

METHODOLOGICAL CHALLENGES

Definitions

In order to understand the difficulties of designing good research with regard to early intervention, a brief explanation of key study components may be helpful.

Randomized Controlled Trials and Background Characteristics

The best type of study design to establish a causal relationship between treatment and outcomes is a randomized controlled trial. Randomized controlled trials are true experimental designs and typically involve a treatment group, in this case early intervention, and a no-treatment group (controls), those not receiving any early intervention. Participants are randomly assigned to one of these groups. The benefit of such a design is that it is the best way to eliminate a *systematic bias* in the groups with respect to attributes (variables) other than, in this case, intervention, that may account for differences in the outcomes of these two groups (Polit and Hungler, 1987). If such a

---

[2] The aim of this program is to increase social interaction skills of children with communication disorders by using parents as interventionists. Mothers are taught to increase the frequency of their child's social interaction by following the child's lead (McLean and Cripe, 1997).

[3] *Naturalistic* infers that learning opportunities take place in naturally occurring activities or interactions and that the intervention revolves around the child's apparent focus of attention (McLean and Cripe, 1997).

design cannot be achieved, these other variables should be 1) discovered and 2) statistically controlled for. Since early intervention is primarily involved with child development (however broadly defined), characteristics of children, families, and programs that could affect child development *outside* of early intervention should be taken into account. Currently well over forty external characteristics (such as child temperament, severity of condition, caregiver education level) are known to affect child development (see Appendix B). Research in this area continues and the more that is understood about child development, the more accurately these characteristics will be identified and their exact effects defined.

Outcomes and Indicators

Outcomes is a term that refers to the desired effect of intervention. In the case of early intervention, one common outcome is child development, which can be construed quite broadly. Typically child development has included cognitive, communication, social/emotional (social competence), adaptive (level of independence), and physical (motor, vision, hearing, health) attributes. Recently it has been expanded to include family outcomes, such as parent-child interaction, which are known to have direct effects on child development (Kelly and Barnard, in press). Indicators are specific measurable attributes that are directly related to the more general outcome. For instance, if parent-child interaction is the outcome under investigation, one specific indicator might be "mother is responsive to child's needs." Once indicators are chosen, the method of measurement can be selected.

Measurement Techniques—Standardized Tests

Two main types of standardized instruments are used to assess outcomes of early intervention: 1) norm-referenced, and 2) criterion-referenced. Such tests include a variety of methods to obtain information such as observation [e.g. *Nursing Child Assessment Teaching Scale* (NCATS) (Barnard, 1978; Barnard et al., 1989; Barnard and Kelly, 1990], questionnaires [e.g., *Family Support Scale* (FSS) (Dunst et al., 1984)], and structured interviews [e.g. *Child Behavior Checklist* (Achenbach and Edelbrock, 1987)].

Norm-referenced Tests

Norm-referenced tests are used to compare the individual child's performance to a group of children who share some specific characteristics such as age. The average performance of the standardization sample (large number of children with similar characteristics) becomes the norm to which an individual child is compared. The norm is thus standardized, and children can be scored on the basis of their performance compared to the standardized norm. (Meisels and Fenichel, 1996). Examples of norm-referenced tests are the Bayley Scales of Infant Development (Bayley, 1993, 2nd edition), *Receptive-Expressive Emergent Language Scale* (Bzoch and League 1991, 2nd edition), *Scales of Independent Behavior* (SIB) (Bruininks et al., 1985), and *Wisconsin Behavior Rating Scale* (Songs et al., 1984).

Criterion-Referenced Tests

A. Domain/Objective Based

A criterion-referenced test rates the child on the degree that the child has mastered a certain domain (such as motor development) or objective (child can stand independently). Development occurs in stages or levels. For instance, a child must have the dexterity to grasp before being able to eat with a spoon. Criterion tests are designed to measure each level of this hierarchy of development, and the score reflects how many levels a child has mastered in a given domain. The key to quality criterion tests is the degree to which they accurately encompass this hierarchy. To assess whether the ordered development in the test reflects actual patterns of child development, it is usually tested on a large population who has some commonality (usually age). Hence criterion tests use norms as well. The subjects are not scored on normative performance, however, but rather are scored on the basis of the level of achievement. Criterion tests are standardized in that each child is rated on the same developmental hierarchy. Examples of criterion-referenced tests are *Batelle Developmental Inventory* (Newborg, et al., 1984) and the *Early Learning Accomplishment Profile* (LAP) (Glover et al., 1995).

B. Curriculum-based Evaluations

Curriculum-based assessment is also criterion referenced, but incorporates specific child and family objectives rather than standardized hierarchies. The purpose of these types of assessments is to design intervention programs for individual children and families. These assessments identify general areas of focus. For example in the Vulpe Assessment Battery (Vulpe, 1979), one of the assessments is "Observe the child's response to stimulation of various sounds, human speech, or adult's smile. The child responds occasionally with vocalization." Scores are designed to indicate frequency of anticipated desired response (for instance, the child responded occasionally with vocalization 5 out of 5 times in similar observational settings, or 4 out of 5 times.) (Meisels and Fenichel, 1996). Examples of curriculum-based evaluations are *Assessment, Evaluation, and Programming System for Infants and Children* (AEPS) (Volumes 1 and 2) [D. Bricker (Vol. 1); J. Cripe, K. Slentz and D. Bricker (Vol. 2), 1993], *Creative Curriculum for Early Childhood* (Dodge and Colker 1992, 3rd edition), and *Every Move Counts* (EMC) (Korsten et al., 1993).

Measurement Techniques—Non-standardized Assessment Tools

Non-standardized refers to a scoring methodology on a particular assessment tool that has not been based on standardized norms or criteria. For example, a particular observation technique was designed to measure how often a child had positive interaction with its mother. The test would first have to define positive interaction, then establish a method for scoring the number of times a child had the defined indicator of positive interaction (e.g. simple counting) and a method for the process of assessment (e.g. observation in a natural setting for 30 minutes, three times a week). Results for this are comparable across different subjects only by the fact that subjects were assessed in the same manner. Whether this particular method may actually measure the positive interaction depends on factors such as the pertinence of the indicator and the accuracy of the observations. While

non-standardized tests may seem less appropriate for research evaluation studies, researchers may be interested in phenomena not well measured by standardized tests. Non-standardized assessments are also very useful for evaluating each child on an individually selected set of objectives. Goal Attainment Scaling (GAS) is an example of a non-standardized assessment. While it provides a method for scoring the degree goals are achieved, it does not determine what the goals are, nor whether they are appropriate for a specific age or condition.

The choice of whether to use standardized or non-standardized tests depends on how accurate the norm or criterion is for the population of interest, how accurate the test is in measuring the phenomena of interest, and whether or not the norm or criterion is appropriate for the particular children and families of interest.

Problems of Research Design in Early Intervention

The Absence of a Control Group

The greatest challenge facing early intervention research for children with disabling or delaying conditions and their families is the absence of an appropriate control group. Due to legal and ethical considerations, a randomly assigned no-treatment group cannot exist. If subjects cannot be randomly assigned to an early intervention treatment group,and a control group, it cannot readily be concluded that changes in child or family development are due strictly to early intervention. As a result, studies that use randomized control designs focus on specific elements of early intervention. For instance, studies may examine the degree of intensity where the treatment group has an added intensity component (Innocenti, 1996; Ramey et al., 1985; Taylor et al., 1993); a specific program component such as Parent Instruction (Innocenti, 1996, Innocenti et. al, 1993); or a specific factor such as age of enrollment (Innocenti, 1996).

Lack of a Comparison Group

A control group indicates those subjects in an experimental study who do not receive the experimental treatment and who have been randomly assigned to the no-treatment group. Outcome scores from the control group are used as a baseline measure against which to contrast the outcome scores of the treatment group. A comparison group is not randomly selected, but provides a group against which to compare scores of the target group. For instance, families who choose not to receive early intervention services even though they qualify would provide a good no-treatment comparison group. These families do not comprise a control group, however, because they were not randomly assigned by the researcher to a no-treatment group. Since comparison groups are not randomly assigned, researchers should be careful to analyze whether there is any systematic bias in the comparison group which may affect outcomes. If there is such a bias, changes in outcomes cannot be conclusively attributed to early intervention. For example, it was found that a hypothetical group of families that chose not to enroll in services although they qualified were three times as likely to be more religious than the target group. To strengthen conclusions, researchers must then discover whether religion might have an impact on the child and family outcomes selected, assess to what degree it has an impact,

and control for that impact. Given that the differences in groups may occur in areas not monitored by the researcher, and the measurement of the impact of significant characteristics (independent variables) might not be feasible, the use of comparison groups can be problematic, but offers a compromise when a true control group cannot be identified. Research projects that use comparison groups are referred to as quasi-experimental—a term that indicates a true control group is not being used in the study.

Since all eligible children must, if desired and accepted by parents, receive early intervention services once identified, the only possible known comparison group for early intervention research is comprised of those who have qualified for services but chosen not to enroll. If such a group could be identified and agreed to cooperate in an evaluative study, the number of subjects would have to be sufficient to control for type of disability, severity, and independent variables. Achieving numbers large enough to attain statistical power is a challenge.

Without a control group, studies should statistically account for differences in child/family outcomes due to factors other than early intervention. While much progress has been made in identifying which factors influence child and family development (Andrews et al., 1995; Boyce et al., 1991; King et al., 1992; Kochanek et al., 1987; Ramey et al., 1978), the sheer number of possible influential factors (independent variables) and their potential causal relationships is daunting. Well over 40 possible program, family and child variables have been recognized as affecting development (Appendix B).

One method that has been employed to address these difficulties uses the child and family as their own controls. Most such comparative approaches contrast actual child development scores to predicted progress scores generated from baseline data obtained before early intervention services began (Burchinal et al., 1994; Hauser-Cram and Krauss, 1991). The drawback to this approach is that measuring the impact of early intervention relies on the accuracy of the predicted score. While this method has some statistical drawbacks (see subsequent study designs that use children and families as their own control and Appendix E), it does provide an accepted methodological alternative in the absence of appropriate comparison groups.

Subject Selection

Given the quantity of independent variables, the number of subjects required to generate statistically significant results is quite large.[4] Studies that attempt to sufficiently control for the effects of independent variables on child and family development should include numbers which allow adequate statistical power (Shonkoff et al., 1988). Acceptable statistical power is achieved when the probability that an effect will be identified if it exists is quite high (80% or more).

[4] Estimating the number of subjects required depends on factors such as the number of independent variables, the power of the analysis, and the effect size the study wishes to measure. For this reason estimates are usually calculated for specific studies using power analysis. For an example, one study which accounted for about 30 independent variables with a medium effect size required a subject number of 200 (Shonkoff, 1992).

Another difficulty with subject recruitment is the use of comparison groups considering the variability in effect of early intervention related to differing conditions. Studies have shown that the impact of early intervention is affected by the severity and type of disabling or delaying conditions (Shonkoff and Hauser-Cram, 1987). Children with mild psychomotor impairments often showed gains (Shonkoff et al., 1992), while children with Down Syndrome tend to show less gain (Guralnick, 1988). It should be pointed out however, that maintaining a child's development level is considered a very positive result for those with Down Syndrome. If the researcher were simply to examine the degree of effect for the group as a whole using numbers only, the gains of the mild psychomotor impaired children would be diluted by the numerical results of the children with Down Syndrome—even though both results are considered positive impacts. A solution is to match children on type and severity of delay, but given the number of variables that should be controlled, generating the numbers needed to achieve statistical power is difficult. Another factor to consider is that with the wide variety of independent variables involved with each child and family, the often unknown etiology of certain conditions, and the specificity of each child's area of concern, accounting for variables between comparison groups becomes a very complex issue.

Data Sources and Measurement

After defining the desired outcomes of early intervention services, selecting an instrument that adequately measures the specified indicators can be problematic. While a host of instruments are available for measuring cognitive and social indicators, often these instruments have some limitations: they are not standardized for populations with disabling or delaying conditions, are not accurate for development in early stages, are not sensitive enough to measure small changes, are not culturally sensitive, and are not valid for the phenomena they are measuring (Hauser-Cram, 1990; Meisels and Fenichel, 1996; Zigler and Balla, 1982). In an article reviewing early intervention program evaluation the author warns:

> [Tests] are widely used because of the large numbers of preschool instruments available, because tests are usually easy to administer and score, and because they possess an aura of objectivity, which researchers find irresistible. However, it would be wise to remember that preschool assessment devices have been criticized as being unreliable, and in many instances, invalid for the purposes for which they are being used (Casto, 1986).

Data sources other than standardized tests include surveys, interviews, observation and non-standardized tests. These methods are often used to supplement standardized tests and to collect enough descriptive data to be able to properly interpret numerical evidence. Given the limitations of standardized tests, researchers recommend using a variety of measurement techniques (Hauser-Cram, 1990). Non-standardized assessments are used in order to customize evaluations specifically to the information researchers are trying to assess. In choosing assessment methods, researchers need to bear in mind the limitations of the methods they choose.

Goals for Study Designs

Several general criteria were identified as important to consider in designing research studies that assess the impact of early intervention service on infants and toddlers with disabling or delaying conditions and their families in Washington State.

The first criterion was that results from the study could be applied to early intervention on a statewide level. Subjects of the study should include the entire population of children with disabling or delaying conditions and their families, or be a representative sample of these children and families. The second criterion was that the outcomes should be comprehensive, reflect the latest developments in the field of child development, and could be tracked over time and provide an ongoing basis of assessment. The third criterion was to identify generally accepted indicators of the selected outcomes through a review of the literature, examination of other studies, and consultation with the Advisory Group.

Many of the problems described above apply to designs presented in the next section. Efforts were made to moderate the significance of these difficulties and steps were taken to control for major characteristics (independent variables), balance quantitative data with qualitative data, and identify appropriate comparison groups. Each study, however, has its own particular strengths and weaknesses. When evaluating a study, these strengths and weaknesses should be weighed carefully.

STUDY DESIGN OPTIONS

Introduction

The following study designs seek to address the question: what is the impact of early intervention on children birth to three, with disabling or delaying conditions and their families in Washington State? The focus of the studies is the assessment of child and family outcomes.

These designs face many of the same problems described above. Because of the absence of a control group for legal and ethical reasons, true experimental studies (randomized controlled trials) are not feasible. As an alternative, comparison groups must be located, or children must serve as their own controls. Each of these options has specific advantages and disadvantages which are explored within each design.

The field of early child development is constantly (and rapidly) evolving. Through consultation of the literature, families, service providers and experts, we have suggested child and family outcomes and data collection methods. New research results undoubtedly will bring changes. For this reason, it should be kept in mind that the outcomes, data collection, and background characteristics suggested in these studies are recommendations that should be revised as new data and methods in the field of early childhood development emerge.

The following six types of studies will be discussed.

STUDY DESIGN TYPES

- Child/Family Serves as Own Control—Large Scale Longitudinal Study
- Child/Family Serves as Own Control—Small Scale Longitudinal Study
- Comparison Group—Longitudinal Study
- Pre-Post Study
- Retrospective Cross-sectional Study
- Key Informant Study— Survey-only and Three-tiered Approach

CHILD/FAMILY SERVES AS OWN CONTROL—LARGE SCALE LONGITUDINAL STUDY

DESCRIPTION

The study will compare predicted changes in child/family development to actual changes in development and will compare baseline data gathered at the pre-test to post-test data. Follow-up assessments will be conducted for both families and children.

OUTCOMES

PHASE ONE

Child Outcomes: (1) Child-Parent Interaction (2) Developmental Skills (3) Health (4) Readiness to Learn

Family Outcomes: (1) Knowledge (2) Empowerment (3) Support (4) Parent-Child Interaction

PHASE TWO

Child Outcomes: (1) Child Relationships (2) Child Behavior (3) School Performance (4) Child's Service Status

Family Outcomes: (1) Transition Experience (2) Impact of Early Intervention

METHODS

(1) Testing—Standardized Testing (2) Survey of Parents (written or phone)
(3) Survey of Teacher (longitudinal); Early Intervention Specialist (birth to three)
(4) Child and Family Observation
(5) Program Services Observation

Major Strengths:

- The study would allow determination of which program components work for which children and families and within group comparisons.
- The design takes into account multiple variables influencing child and family outcomes and reflects current recommendations regarding early intervention research.
- The study allows for longitudinal tracking.

Major Weaknesses:

- The change score models pose some statistical problems.
- Estimated cost and time of completion.

ESTIMATED DIRECT COST:	**$3,200,000—$3,600,000**
ESTIMATED COMPLETION TIME:	**10 years**

CHILD/FAMILY SERVES AS OWN CONTROL—LARGE SCALE LONGITUDINAL STUDY

SUMMARY

This study is a non-experimental, longitudinal project which will examine the impact of Washington State early intervention services on children with delaying or disabling conditions and their families. *Children and families serving as their own control* means that this study does not have a separate control or comparison group. The study will essentially measure changes in each individual and family that have occurred during the course of intervention, and compare beginning outcome data to outcome data at future points in time for each subject. Predicted changes in child/family outcomes also will be compared to actual changes in development using interval[5] standardized test scores. Outcomes which are not measured by interval scores will compare baseline data gathered at the pre-test to post-test data, only. Follow-up assessments will be conducted for both families and children in the form of child observation, and parent/teacher surveys and interviews.

The study consists of two parts: Phase I examines child and family progress over the course of continuous early intervention enrollment; Phase II involves a follow-up survey/interview of families/teachers when children are ages 5 and 7 which 1) ascertains whether children are enrolled in special education, 2) describes their transition experience, 3) describes the child's relationships, behavior, and school performance, and 4) describes the family's opinion of early intervention. Subjects are stratified by type of delay, and categorized as either moderate or severe in terms of severity of condition.

INTRODUCTION

The purpose of this study is to measure the impact of early intervention on Washington children with delaying or disabling conditions and their families by adopting proven methods of predicted change scores, controlling for determining characteristics, and accounting for differences in the large array of delaying conditions.

If subjects cannot be randomly assigned to treatment (early intervention) and no-treatment (no early intervention) groups, it is difficult to conclude that changes in child/family development are due specifically to early intervention. To control for effects on child/family outcomes other than early intervention, characteristics which affect these outcomes should be taken into account. The validity of some first generation research is questioned due to the fact that influences affecting children and families other than early intervention had not been evaluated (Farran, 1996).

With the difficulties involved in identifying an appropriate control group, some studies have relied on using each child as its own control. Second generation research has tried to redress some of the difficulties with such an approach by designing studies that: 1) control

[5] An interval score is a measure that is ranked on a scale that has equal distance between points on that scale.

for determining characteristics (Shonkoff et al., 1992), and 2) pose an alternative comparison method, such as residual change scores (Fewell and Glick, 1996; Oelwein et al., 1985). Most such comparative approaches contrast actual child development scores to predicted progress scores generated from baseline data obtained before early intervention services began (Burchinal et al., 1994; Hauser-Cram and Krauss, 1991).

Recent research stresses that in order to measure the efficacy of early intervention more accurately, studies should take into account the variety of child/family characteristics and the specific program components with which they interact. By law, services must be individualized (and therefore different) for every child and family. Since the nature of disabilities and background characteristics are so varied, program components will affect *each* child and family differently. For instance, more intensive intervention may produce dramatic improvements for a child with one disability; whereas a child with a different disability may achieve the same amount of progress without added intensity. If services are not individualized, children and families do not receive the full benefit of services and progress towards outcomes is jeopardized.

METHODS

Recruitment Sites

This study relies on recruitment of children with the assistance of service providers in each of Washington's 39 counties who agree to participate. Participating sites will include a variety of urban, suburban, and rural areas.

Eligibility Criteria

The target population is all birth to three children and their families newly enrolled in early intervention services in Washington State. Children will be selected in the three following categories: 1) Down Syndrome, 2) motor impairment, and 3) developmental delay.

Sample Size

The ideal size of the study, accounting for a 30% attrition rate over time, would be approximately 260 subjects (α=.05, statistical power is at .80, and effect is ~.33). The sample size will be divided as follows: n (Down Syndrome)=50, n (motor)=50, n (delay)=160. Separating groups by type of disability will allow a more detailed analysis of change scores.

Recruitment of Children and Families

At the time of initial referral, participating service providers will inform the parent about the existence of the study if it is likely that the child will meet study criteria. A pamphlet will be provided which explains the process, focus and design of the study, and which asks the family's permission to be contacted by the research team. If a family declines, non-identifiable demographic data should be collected for comparison of non-participating to participating children and families. If a family agrees, the research staff will contact them

to describe the study further, answer questions, and obtain written consent. After the paperwork is completed, subjects will be assessed to obtain baseline data at T_1 no more than 4-6 weeks after initial assessment.

Child Characteristics

A review of the literature (please see the subsequent section, Discussion) indicates that many characteristics can affect the development of children with disabling or delaying conditions. For this study seven characteristics have been selected: 1) gender, 2) birthweight, 3) age, 4) age at enrollment, 5) health status, 6) temperament, and 7) severity of condition. Characteristics 1-4 can be obtained from a review of the child's intake information by research staff. To assess child health status, trained research staff will utilize *General Health Ratings Index* (Eisen et al., 1980). To obtain child temperament information, trained research staff will conduct an evaluation using the *Carey Infant Temperament Scale* (ITQ) (Carey and McDevitt, 1978). Severity of condition will involve two categories: 1) mild-moderate and 2) moderate-severe, where group one indicates children with a Mental Development Index (MDI) of less than 50, and group two indicates an MDI of 50 or greater. Mental development will be measured by research staff at the start of the study using the *Bayley Scales of Infant Development* (Bayley, 2nd edition, 1993).

Family Characteristics

Family characteristics will include the following: 1) primary caregiver's[6] education level, 2) family's yearly income, 3) family's category of residence (urban, small urban, rural), 4) ethnicity, 5) quality of home environment, 6) family's social support resources, and 7) primary caregiver's health status. Characteristics 1-4 can be gathered at intake. The family's home environment will be evaluated by trained researchers using *Family Interactive Scales* (FIS) (Kracke, 1981; Riskin and Faunce, 1982; Walsh and Wood, 1983). The family's degree of social support will be measured by trained researchers using the *Social Support Questionnaire* (Sarason et al., 1983).

Program Characteristics

Recent research has explored the importance of matching particular program elements to specific needs of children and families. Within this paradigm, certain program characteristics have emerged as key characteristics. Of those characteristics this study will examine: 1) location of services (home-based, center-based, mixed), 2) type of service (multidisciplinary, single disciplinary), 3) monthly duration (total mean hours per month), 4) service structure (individual, group, both), 5) degree of structure (very structured, somewhat structured, loosely structured) 6) amount (if any) of other services.

---

[6] With regard to characteristics, *primary caregiver* is used in this report in place of *mother* to include situations where the child is living with a caregiver other than or in addition to the mother. It should be noted that the literature usually refers to these characteristics as *mother's* health and *mother's* education level.

The types of services and their characteristics will be noted by early intervention staff on *Monthly Service Records*. Parents will be asked whether they are receiving any other services periodically (approximately every six months) through the course of the study.

To provide program service information, services will be observed every six months to validate information presented in the *Monthly Service Reports*.

Phase I

Child Outcomes and Measures

These outcomes reflect the growing trend in early intervention evaluation which recognizes that the purpose of early intervention is to encourage children with delaying or disabling conditions and their families to become contributing members of society. Child outcome assessment will occur in four domains: 1) Developmental Skills, 2) Health, 3) Child-Parent Interaction, and 4) Readiness to Learn.

Developmental skills incorporate the five basic development areas which are assessed in order to qualify for early intervention services: 1) cognitive development, 2) communication, 3) social competence (social/emotional), 4) adaptive (level of independence), and 5) physical (vision, hearing, motor). The child health outcome incorporates the idea that the child receiving services has the best possible health. The outcome, school readiness, reflects the general ability of children to learn in school. The educational experience is important for all children in that it forms the basis for further learning throughout their lives. It has been determined that five attributes enable children to do well in school. They are confidence, curiosity, persistence, capacity to communicate, and capacity to get along with others. Such qualities are developed in children *within the first three years of life*. It is especially important for children with disabling or delaying conditions to develop school readiness. The more children are ready to learn, the more they can contribute to the classroom, to the work force, and to society (*Heart Start: The Emotional Foundations of School Readiness*, 1992). For the outcome, child-parent interaction, two indicators have been selected, responsivity and reciprocity. Responsivity refers to the degree which the child initiates interactions with the parent, and the degree of receptiveness the child exhibits towards parent-initiated interactions. Reciprocity indicates the degree which the child understands the intention of the parent's interaction.

Standardized tests designed for these specific outcomes will be used for assessment. The instruments specified in the following table are suggestions only. The research team should review the literature at the time of the study as instruments are constantly under review and undergo revision.

CHILD OUTCOMES, INDICATORS, AND SUGGESTED INSTRUMENTS

Child Outcomes	Suggested Instruments
1) Developmental Skills a. cognitive development b. communication c. social competence (social/emotional) d. adaptive (level of independence) e. physical (motor, vision, hearing)	Standardized Tests [e.g. *Pediatric Evaluation of Disability Inventory (PEDI)* (Hayley et al., 1992); *Developmental Sequence Performance Inventory* (DSPI) (B to 8); *MacArthur Communication Development Inventory* (Fenson et al., 1993)]
2) Health a. children have the best possible health	Standardized Lists [e.g. *General Health Ratings Index* (Eisen et al., 1980)]
3) Child-Parent Interaction a. responsivity b. reciprocity	Standardized Tests [e.g. *Nursing Child Assessment Teaching Scale* (NCATS) (Barnard, 1978; Barnard et al., 1989; Barnard and Kelly, 1990)]
4) Readiness to Learn a. confidence b. curiosity c. persistence d. capacity to communicate e. capacity to get along with others	Standardized Tests [e.g. *Bayley Scales of Infant Development* (Bayley, 2nd edition, 1993), *EICS Observation Scale of Children's Spontaneous Play* (Belsky et al., 1983)]

Family Outcomes and Measures

Four family outcomes have been selected for this study: 1) knowledge, 2) empowerment, 3) parent-child interaction, and 4) social support. Under the broad outcome category of knowledge, three indicators will be examined: 1) knowledge of child's disability, 2) understanding what the child needs to enhance development, and 3) ability to read child's cues. Input from parents along with family outcomes conceptualized by some researchers confirm that these are four desirable family outcomes of early intervention (Bailey et al., 1998; Goldberg, 1977; Turnbull et al., in press). Knowledge is considered essential to foster the family's capacity to enhance their child's development.

Empowerment has been defined by Staples (1990) as "the ongoing capacity of individuals or groups to act on their own behalf to achieve a greater measure of control over their lives and destinies." Empowerment may include a sense of self-efficacy and the perception of control over life events (Bailey et al., 1998; Conger and Kanungo, 1988). Dunst et al. (1988) and Turnbull and Turnbull (1997) see empowerment as the degree to which family members perceive they can negotiate the system and feel a sense of efficacy or control over access to supports and services. The three indicators chosen for empowerment are the following: 1) confidence in ability to enhance child's development, 2) confidence in ability to interact with professionals and advocate for services, and 3) locus of control (perception of self-empowerment).

The importance of parent-child interaction is well noted in the literature (Barnard et al., 1989; Barnard and Kelly, 1990; Kelly and Barnard, in press; Resnick et al., 1988; Seifer and Sameroff, 1991). Two indicators of parent-child interaction, responsiveness and reciprocity, have been selected for the study. Responsiveness is the ability of the parent to initiate desired interactions with the child and respond to child initiated interaction. Reciprocity is the degree to which the parent can successfully communicate with the child.

The emergence of social support as an important factor directly affecting child and family development has drawn value and importance to the role of early intervention in helping to establish social support networks (Dunst, et al., 1997). Turnbull and Turnbull (1997) suggest that early intervention services can assist parents in generating support networks which facilitate acquiring basic economic and social needs. Two indicators chosen for this outcome are economic and social support. Economic support refers to the ability of the family to provide basic needs such as food, shelter, clothing, and medical attention (Turnbull and Turnbull, 1997). While providing economic support is not a direct role of early intervention , linking families to services such as Medicaid, Supplemental Security Income, and housing, food, and economic assistance is critical to establishing a healthy developmental environment for children. Social support refers to the existence of a network of contacts that can fulfill the family's needs on a variety of levels (Dunst et al., 1997).

Standardized tests designed for these specific outcomes will be used for assessment. The instruments specified in the following table are suggestions only. The research team should review the literature at the time of the study as instruments are constantly under review and undergo revision.

FAMILY OUTCOMES, INDICATORS, AND SUGGESTED INSTRUMENTS

Family Outcomes	Suggested Instruments
1) Knowledge a. knowledge of child's disability b. understanding what the child needs to enhance development c. ability to read child's cues	Standardized Tests [e.g. *Parent as a Teacher Scale* (PAAT) (Strom, 1984)]
2) Empowerment a. confidence in ability to enhance child's development b. confidence in ability to interact with professionals and advocate for services c. locus of control (perception of self-empowerment)	Standardized Tests [e.g. *Parent Self-awareness Scale* (Snyder et al., 1985), *Child Improvement Locus of Control Scales* (Devellis et al., 1985)]
3) Parent-Child Interaction a. responsivity b. reciprocity	Standardized Tests [e.g. *Nursing Child Assessment Teaching Scale* (NCATS) (Barnard, 1978; Barnard et al., 1989; Barnard and Kelly, 1990)]
4) Support a. family has economic resources b. family has social support	Standardized Tests [e.g. *Family Support Scale* (FSS) (Dunst et al., 1984), *Social Support Resource Scale* (Vaux and Harrison, 1985)]

Data Collection

Tests will be conducted by a team of three members of the research staff who have been trained in test administration. Questionnaires will be left to be filled out by the parents. Any assessment can be rescheduled per parent request. Phase I of the study will track from B-3 years, with reevaluation occurring every six months. The times are as follows: T_1=within 4-6 weeks after provider notification; T_2, T_3, T_4 at 6 month intervals.

Data Analysis Methods

1) Test Outcomes (e.g. Proportional Change Index, Growth Curve Analysis)

Residual Change Scores for interval scores will be used. These scores compare predicted change scores to actual change scores. The predicted scores are calculated applying a regression equation which uses the following: a) individual's pre-test score b) distribution of sample score at T_1 c) relation between T_1 score and T_2 score for the entire sample (slope of regression) and d) distribution of scores at T_2. The residual change score is the difference between the individual's actual and predicted score. Its main use is to compare the degree a child and family have changed within the context of the study group. Other statistical methods, such as Growth Curve Analysis, are available and should be considered when the research project is finalized. Different statistical models offer various strengths. For instance, Growth Curve Analysis is prevalent in research studies and is thought to provide a more accurate predicted score than other models (see Hatton et al., 1997). The Residual Change Score model can accommodate a greater variety of assessment measures than Growth Curve Analysis. Once the selection of outcome measures and instruments are finalized, researchers should carefully review these models. (For a summary of predicated change score statistical models see Appendix E.)

The Change Score Model also will be used. This model is often referred to as *simple change score*—which indicates that a straight comparison between scores taken at different times will occur. Assessments which do not have interval scores will use the change score model only. The main purpose of this model is to measure how *each* child and family changed. While this model has statistical drawbacks (see Weaknesses), it does offer a view to child progress that does not rely on the performance of the group as a whole.

2) Multivariate Analysis (multiple regression, partial correlation, etc.)

Multiple regression will be used. Multiple regression is a statistical procedure for understanding the simultaneous effects of one or more characteristics (independent variables) on a dependent variable (early intervention). Its main use will be to analyze how various child, family, and program characteristics affected outcomes.

Phase II

Phase II would involve follow-up surveys, interviews, and observations when children are ages 5 and 7. The number of study subjects would equal all those original study participants still trackable. Parents and teachers would be surveyed regarding the domains depicted in the following table.

DATA SOURCES AND DOMAINS OF FOLLOW-UP ASSESSMENT

Parent survey/interview	Teacher survey/interview	Observation
Child's Service Status	School Behavior (child)	Child Relationships
Transition Experience	School Performance (child)	School Behavior
Child Behavior		School Performance
Opinion of Early Intervention		In-school Setting
Parents' Social Relationships		

Some standardized tests already developed would be appropriate for this follow-up [such as *Child Behavior Checklist* (CBCL) (Achenbach and Edelbrock, 1987)]. It is worth considering non-standardized assessments [such as *Inclusion Outcomes Rating Scale* (Peck et al., 1992)] or surveys and interviews in order to include open-ended questions which would present an overall impression of how the children and families are doing at each of the assessment times (when the child is 5 and 7 years of age). Observation, interviews, and surveys would provide a variety of measurements to obtain a comprehensive description of child and family status at the chosen time periods.

TABLE OF DATA, SOURCES, AND TIME OF DATA COLLECTION

DATA	SOURCE	Re-cruit-ment	B to 3	5 & 7 yrs
CHILD/FAMILY/PROGRAM CHARACTERISTICS				
Child Characteristics:				
gender	intake information	X		
birthweight	intake information	X		
age	intake information	X		
age @ enrollment	intake information	X		
health status	*General Health Ratings Index*	X		
temperament	*Carey Infant Temperament Scale*	X		
severity of condition	*Bayley Scales of Infant Development*	X		
Family Characteristics:				
primary caregiver's education level	intake information	X		
yearly income	intake information	X		
location of residence	intake information	X		
ethnicity	intake information	X		
primary caregiver's health	intake information (parent)			
home environment	*Family Interactive Scales*	X		
social support resources	*Social Support Questionnaire*	X		

DATA	SOURCE	Re-cruit-ment	B to 3	5 & 7 yrs
Program Characteristics				
location of services	*Monthly Service Record* & Observation		X	
type of service	*Monthly Service Record* & Observation		X	
hours per month	*Monthly Service Record* & Observation		X	
service structure	*Monthly Service Record* & Observation		X	
degree of structure	*Monthly Service Record* & Observation		X	
receipt of other services	intake information (parent)	X		
PHASE I				
Child Outcomes/Indicators:				
Child-Parent Interaction				
responsivity	Standardized Tests		X	
reciprocity	Standardized Tests		X	
Developmental Skills				
cognitive development	Standardized Tests		X	
communication	Standardized Tests		X	
social competence (social/emotional)	Standardized Tests		X	
adaptive (level of independence)	Standardized Tests		X	
physical (motor, vision, hearing)	Standardized Tests		X	
Health				
children have the best possible health	Standardized Lists		X	
Readiness to Learn				
confidence	Standardized Tests		X	
curiosity	Standardized Tests		X	
persistence	Standardized Tests		X	
capacity to communicate	Standardized Tests		X	
capacity to get along with others	Standardized Tests		X	

DATA	SOURCE	Re-cruit-ment	B to 3	5 & 7 yrs
Family Outcomes/Indicators:				
Knowledge				
knowledge of child's disability	Standardized Tests		X	
understanding what the child needs to enhance development	Standardized Tests		X	
ability to read child's cues	Standardized Tests		X	
Empowerment				
confidence in ability to enhance child's development	Standardized Tests		X	
confidence in ability to interact with professionals and advocate for services	Standardized Tests		X	
locus of control (perception of self-empowerment)	Standardized Tests		X	
Support				
economic resources	Standardized Tests		X	
social support	Standardized Tests		X	
Parent-Child Interaction				
responsivity	Standardized Tests		X	
reciprocity	Standardized Tests		X	
PHASE II				
Parent:				
Child's service status	Non-standardized Assessments			X
Child's transition experience	Non-standardized Assessments			X
Child behavior	Non-standardized Assessments			X
Opinion of EI	Non-standardized Assessments			X
Parents' social relationships	Non-standardized Assessments			X
Teacher:				
School behavior (child)	Non-standardized Assessments			X
School performance	Non-standardized Assessments			X
Child Observation:				
Relationships	Non-standardized Assessments			X
School behavior	Non-standardized Assessments			X
School performance	Non-standardized Assessments			X
In-school setting	Non-standardized Assessments			X

TIMELINE

The total time for the study is estimated at 10 years.

TIMELINE FOR CHILD/FAMILY SERVES AS OWN CONTROL—LARGE SCALE LONGITUDINAL STUDY

STUDY YEAR	1	2	3	4	5	6	7	8	9	10
Age of Year 2 Subjects		.5-3 years	1.5-4 years	2.5-5 years	3.5-6 years	4.5-7 years	5.5-8 years	6.5-9 years		
Age of Year 3 Subjects			.5-3 years	1.5-4 years	2.5-5 years	3.5-6 years	4.5-7 year	5.5-8 years	6.5-9 years	
Organize Study*	X									
Recruit		X	X							
Phase I		X	X	X	X	X				
Phase II				X	X	X	X	X	X	
Analysis Phase I						X				
Completed Report										X

* (hire staff, Human Research Review Board, establish criteria, establish recruiting sites)

DIRECT COST ELEMENTS

Cost estimates include only the direct costs of conducting the study. Indirect cost rates (to cover organizational overhead) vary widely depending on the type of organization, such as university, for-profit research center, or state agency. Depending on the specific indirect cost rate, indirect costs may represent 10 to 60 percent, or more, of the direct costs. With additional expenses for rent or lease for project space and indirect costs, total costs (direct plus indirect) could be **double** the estimated direct costs presented. This study will incur the following direct cost elements:

* Participant Payment—subjects and service providers will be reimbursed for their time/effort in participation of the study
* Research Staff
* Supplies/Equipment
* Other (e.g. travel, postage)

TOTAL ESTIMATED DIRECT COST: $3,200,000—3,600,000

DISCUSSION

Previous Studies

One difficulty facing studies of this nature is the number of subjects required to carry out multivariate analysis. The greater the number of variables included in the study, the more study subjects are required. As a result, many studies using the predicted change score model have taken into account too few determining child/family characteristics and have focused on evaluating a single program component or model (Caro and Derevensky, 1991, 1991; Wolery et al., 1985). Few have been longitudinal. Although results have been positive for child development (Bailey and Bricker, 1985; Caro and Derevensky, 1991; Fewell et al., 1996; Hanson, 1985; Oelwein et al., 1985; Wolery et al. 1985), family resources and support (Caro and Derevensky, 1991), family skills (Bailey and Bricker, 1985; Caro and Derevensky, 1991; Hanson, 1985), and parent satisfaction (Bailey and Bricker, 1985; Hanson, 1985), these results have to be considered within these methodological shortcomings.

One study which has generated the required number of subjects to carry out valid multivariate analysis was able to demonstrate the positive effects of early intervention by specifying which components of early intervention succeeded for which type of child and family (Shonkoff et al., 1992). These findings have shaped current research in the recognition that early intervention is "a complex and multidimensional experience that defies simple description" (Shonkoff et al. 1992). Short of a randomized control group study, the accurate assessment of the general impact of early intervention largely depends on the accuracy in, and ability to control for, contributing developmental factors of *each* family and child. Implications are that future research should be multidimensional (Guralnick, 1997; Hauser-Cram, 1990).

Characteristics

Past research is rich in terms of which variables predict developmental delay (*Healthy People 2000*, 1991; King et al., 1992; Rojahn et al., 1993), but to what degree these characteristics affect developmental progress in the long term is less conclusive. Child characteristics used in this study represent those that are currently considered to be primary influencing factors in child development (King et al., 1992; Kochanek et al., 1987). The family characteristics in this study are those thought to impact child and family development (Boyce et al., 1991; Andrews et al., 1995; King et al., 1992; Ramey et al., 1978). More than forty-five characteristics thought to influence the development of children with delaying or disabling conditions and their families have been noted in previous studies or the early intervention research. Due to feasibility concerns, this study takes into consideration only those characteristics that are most prevalent in current literature.

Recent research has produced numerous studies on the impact of specific elements of intervention programs (Bennet and Guralnick, 1991; Casto and White, 1993; Ramey et al., 1992; Seifer et al., 1991; Taylor, 1993). Program components in this study have been

drawn from this body of work, and from similar studies which suggest that other external elements, such as location of service center (rural or urban), may influence effectiveness (Lonner et al., *Exploratory Study of Barriers to Birth to Three Services*, 1994). Similar to child and family characteristics, program components have been narrowed to those most predominant in contemporary research.

Outcomes

Part of the purpose of early intervention is to assist children in developing skills that will allow them to participate in valued roles in the community, perform to the best of their ability in school and be able to become contributing members of society. To assess these goals, outcomes other than IQ, such as adaptive, communication and social skills have become prevalent (Guralnick, 1991 and 1989; Casto and Lewis, 1984; Hauser-Cram and Shonkoff, 1988). The outcomes in this study were chosen from stated goals in national Part H legislation [Individuals with Disabilities Education Act (IDEA), 1997], recommendations from national councils on early education (*Outcome Measures for Early Intervention Services*, Accreditation Council for People with Disabilities, 1995; *Starting Points*, Carnegie Foundation, 1994; *Healthy People 2,000*, 1991; *Heart Start: The Emotional Foundations of School Readiness*, 1992), the literature (Guralnick, 1997; Shonkoff et al., 1992), and recommendations from the Advisory Group of this project (1998).

Since the passage of Part H, programs have emphasized family centered services and in so doing have generated a new direction of early intervention research. While previous studies focused solely on child development, current research has begun to discuss and assess impact of early intervention on families especially in the areas of family support, family empowerment, parent child interaction, and the skills needed to enhance a child's potential for development (Boyce, 1993; Casto and White, 1993; Cleary, 1988; Crowley and Taylor, 1993-4; Gallagher, 1996; Kelly and Barnard, in press; Turnbull et al., in press). Family outcomes in this study reflect these categories.

ISSUES

General Issues

Consideration should be given to general social science research difficulties. While the methodology addresses some of these problems, the final study report should address issues such as:

- Generalizability
- Possible Threats to Validity
  - ◊ Selection effects (biases in the study sample, absence of a control group)
  - ◊ Hawthorne effect (especially pertinent for ratings obtained by observation)
  - ◊ Testing effects (given the amount of re-testing, this could be a problem; although less so for observable phenomena)
  - ◊ History
  - ◊ Attrition

- Problems of instrument sensitivity

Additional consideration should be given to the feasibility issues of the study. The time required to achieve reasonable numbers of subjects and collect data is estimated at 10 years. Success of recruitment will depend on extent of participation among providers, frequency of conditions, and refusal rates. It might be difficult to recruit 260 subjects. If this is the case, the study could take longer than 10 years.

Strengths

One major strength of this study is its comprehensiveness in addressing many of the shortcomings of other early intervention research such as failure to take into consideration determining independent variables, low subject numbers, and inadequate comparison groups. In this study, frequently cited program, family, and child characteristics have been selected. In controlling for these independent variables known to affect child development, conclusions regarding the effect of early intervention on child development can be drawn more reliably than if these characteristics were not taken into consideration. The study will also allow analysis of how these characteristics interact.

Another major strength is that by using children as their own controls, researchers will be able to draw conclusions regarding *each* child and family. Given the diversity of conditions, learning styles, and independent variables affecting development, the definition of *positive impact* is different for every child and family. By isolating which program techniques work for which types of children and families, program personnel, government agencies, and legislators will be able to analyze how to use resources effectively and efficiently. Using children and families as their own controls avoids numerical difficulties in drawing general conclusions. As discussed earlier in this chapter, positive impact can occur on many levels—*maintenance* of developmental achievements can be a very positive impact for one child, whereas *increase* of developmental levels are expected for other groups of children. A comparison of the numerical results of a child who maintains a level of development to one who improves might dilute the overall numerical gain. If the progress of *each* child and family is reviewed, however, conclusions regarding each study participant can be drawn and will not be lost in a larger picture that does not explain important details.

This particular methodology also facilitates within group comparisons. Data from subjects who do particularly well can be analyzed to ascertain which particular children and families respond positively to which program elements. General conclusions regarding the degree of change of study participants can be obtained through residual change scores. Using residual change score methods allows general conclusions to be drawn regarding the progress of the entire group as well as a particular subjects' progress within than group. Thus this study provides both individual assessments, and within group assessments. A general group assessment can be made with regard to whether the group as a whole improved by comparing group baseline data to data gathered at future points in time and using comparative residual change scores.

Weaknesses

The study has numerous drawbacks, some of more concern than others. One difficulty is the choice of characteristics (independent variables). A range of child, family, and program characteristics known to affect child development has been selected for this study. Such characteristics must be controlled for in order to attribute changes in child and family outcomes to early intervention, and not to other variables. *All* characteristics have not been taken into consideration; in part because all of them are not known, and in part because generating the subject numbers necessary to control for all known independent variables would not be feasible. In addition, some chosen characteristics may face problems of definition. For instance, one of the selected program characteristics is *degree of structure*. Researchers should determine in advance what will constitute a *highly* structured program as opposed to a *loosely* structured program, and who will be rating the program on structure—the service provider or researcher.

A major problem with the design is that the strength of the conclusions rely on the acceptance of the validity of predicted change scores and simple change scores. Both of these processes have statistical drawbacks (see Appendix E). The main concern with the residual change score model is that it relies heavily on group changes since part of the regression equation predicting how an individual child will change depends on how the group as a whole changes. In this way, progress is a relative measure. The main concern with simple change scores is that the reliability of the standardized tests creates statistical problems. When comparing changes, the error in each individual measure is compounded. For example, a child scored 13 points on a curiosity scale and the test was accurate to within 2 points. The child's actual score may be as low as 11 or as high as 15. The same child scored 15 on the next test and again, the test is accurate to within two points. The second score could be as low as 13 or as high as 17. In terms of accuracy, while the obvious simple change score is *2* (13:15) a possible change score may be *6* (11:17) or *0* (13:13). The variety in these scores undermines the accuracy of the measure of change.

A related weakness is the general problem with instrument validity and sensitivity. Measuring such concepts as *curiosity* or *perception of self-confidence* is difficult, especially in the age range of birth to three. This design relies heavily on standardized testing. It should be kept in mind, however, that despite vast improvements over the last decade, testing still lacks the validity researchers would like to see and problems with cultural sensitivity, accuracy in measuring the outcome or indicator, relevance for the population with disabling or delaying conditions, and sensitivity to small changes still exist.

It also should be noted that given the amount of testing and information collection, the study might be intrusive for participants. In addition, time and money factors associated with this study should be considered carefully. While it is beneficial to follow subjects longitudinally, a ten-year study is a large commitment of time and resources. During the time of the study, many changes may occur which affect early intervention programs and the way they are implemented. How future changes will influence the results and continuance of the study is unknown.

SUMMARY: STRENGTHS/WEAKNESSES/TIME/ESTIMATED DIRECT COST

Major Strengths:

- The study would allow determination of which program components work for which children/ families.
- The design takes into account the multiple variables influencing child and family outcomes.
- The design reflects current recommendations regarding early intervention research.

Major Weaknesses:

- Conclusions rely heavily on residual change score and change score models.
- There may be a significant problem recruiting enough study subjects.
- Instrument sensitivity, validity.
- Estimated cost and time of completion.

ESTIMATED DIRECT COST: **$3,200,000—$3,600,000**

ESTIMATED COMPLETION TIME: **10 years**

CHILD/FAMILY SERVES AS OWN CONTROL—SMALL SCALE LONGITUDINAL STUDY

DESCRIPTION

The study will compare predicted changes in child and family outcomes to actual changes in outcomes and will compare baseline data gathered at the pre-test to post-test data.

OUTCOMES

Child Outcomes: (1) Child-Parent Interaction (2) Developmental Skills (3) Health (4) Readiness to Learn

Family Outcomes: (1) Knowledge (2) Empowerment (3) Support (4) Parent-Child Interaction

METHODS

(1) Testing
   a. Standardized
   b. Non-standardized
(2) Annual Review of Individualized Family Service Plans (IFSPs)
   a. Services Correspond to Parent Choice
   b. Developmental Progress of Child
(3) Interview of Parents (4) Program Service Observation
(5) Observation of Child and Family (6) Case Studies

Major Strengths:

- The study would allow determination of which program components work for which children/ families.
- The design takes into account multiple variables influencing child and family outcomes.
- The design reflects current recommendations regarding early intervention research.
- The study is comprehensive in that it provides a framework to ground conclusions in both qualitative and quantitative data.

Major Weaknesses:

- The residual change score model can only be used for quantitative data with interval scores.
- There are statistical problems with change scores using quantitative data.

ESTIMATED DIRECT COST:	**$1,400,000**
ESTIMATED COMPLETION TIME:	**3.5 years**

CHILD/FAMILY SERVES AS OWN CONTROL—SMALL SCALE LONGITUDINAL STUDY

SUMMARY

This study is a scaled down version of the previous large scale study where children and families serve as their own control. In this study, the school-age longitudinal element has been removed, and the number of standardized tests have been vastly reduced and replaced with a number of different assessment approaches. Recruitment, eligibility requirements, background characteristics and methods for obtaining them, and the relevant literature are the same as the larger study. Child and family outcomes and indicators are also the same. The number of subjects has been reduced from 260 to 220, with the expectation that a shorter study will have a lower attrition rate (10 percent). The discussion which follows concentrates on those elements which differ in the study.

INTRODUCTION

The previous study relies heavily on standardized tests. While these tests include a variety of techniques to gather information such as observations [e.g. *Nursing Child Assessment Teaching Scale* (NCATS) (Barnard, 1978; Barnard et al., 1989; Barnard and Kelly, 1990], questionnaires [e.g. *Family Support Scale* (FSS) (Dunst et al., 1984)], and structured interviews [e.g. *Child Behavior Checklist* (CBCL) (Achenbach and Edelbrock, 1987)], current thought in early intervention assessment suggests that "high quality assessment includes the use of several types of instruments and methods, such as informal and formal testing, observation, and interviews" (Bagnato et al., 1997). Given the problems associated with standardized tests (see the section Methodological Challenges in this chapter), research in early intervention has stressed the importance of balancing the results of these tests with informal measures and qualitative information (Bagnato et al., 1997; Meisels and Fenichel, 1996). Often referred to as *triangulation of measurement*, this method provides a constructive and comprehensive assessment of the impact of early intervention as results can be interpreted on a variety of levels. The principle of triangulation of measurement involves the use of a variety of qualitative and quantitative data in order to interpret these results within a fuller framework. If data from standardized tests, informal assessment, interviews, and observations can be drawn together to make conclusions, these conclusions are better grounded than those that rely on a single type of assessment method which may or may not portray an accurate picture.

This smaller scale study includes the use of standardized tests along with informal measures, structured and non-structured observation, and open-ended interviews. Also included are a small number of case studies to use as the descriptive context within which to interpret quantitative data.

The following table summarizes the similarities of this study and the previous one in terms of characteristics and their methods of collection, outcomes, and indicators.

SUMMARY OF CHARACTERISTICS, OUTCOMES, AND INDICATORS

OUTCOMES	
CHILD	**FAMILY**
Developmental Skills cognitive development communication social competence (social/emotional) adaptive (level of independence) physical (motor, vision, hearing) Health children have the best possible health Child-Parent Interaction responsivity reciprocity Readiness to Learn confidence curiosity persistence capacity to communicate capacity to get along with others	Empowerment confidence in ability to enhance child's development confidence in ability to interact with professionals and advocate for services locus of control (perception of self-empowerment) Knowledge knowledge of child's disability understanding what the child needs to enhance development ability to read child's cues Parent-Child Interaction responsivity reciprocity Support economic resources social support

CHARACTERISTICS	
Child Characteristics:	**Data Source**
1) gender 2) birthweight 3) age 4) age @ enrollment	intake information
5) health status	*General Health Ratings Index*
6) temperament	*Carey Infant Temperament Scale*
7) severity of condition	*Bayley Scales of Infant Development*
Family Characteristics	**Data Source**
1) primary caregiver's education level 2) yearly income 3) location of residence 4) ethnicity 5) primary caregiver's health	intake information
6) home environment	*Family Interactive Scales*
7) social support resources	*Social Support Questionnaire*
Program Characteristics	**Data Source**
1) location of services 2) type of service 3) hours per month 4) service structure 5) degree of structure	*Monthly Service Record* & Program Observation
6) receipt of other services	Parent

METHODS

Child Outcomes and Measures

Child outcome assessment will occur in four domains: 1) Developmental Skills, 2) Health, 3) Readiness to Learn, and 4) Child-Parent Interaction. Developmental skills incorporate the five basic development areas which are assessed in order to qualify for early intervention services: 1) cognitive development, 2) communication, 3) social competence (social/emotional), 4) adaptive (level of independence), and 5) physical (vision, hearing, motor). School readiness essentially reflects the general ability of children to learn in school. The five selected indicators are confidence, curiosity, persistence, capacity to communicate, and capacity to get along with others. Child-Parent interaction indicators are responsivity and reciprocity. (For a description of outcomes and indicators see Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter.)

Child Development will be measured by a norm-referenced standardized test such as *Bayley Scales of Infant Development* (Bayley, 2nd edition, 1993) or *Pediatric Evaluation of Disability Inventory* (PEDI) (Hayley et al., 1992), a curriculum-based standardized test, such as *Assessment, Evaluation, and Programming System for Infants and Children* (AEPS), Volumes 1 and 2 [D. Bricker (Vol. 1); J. Cripe, K. Slentz and D. Bricker (Vol. 2), 1993)], and unstructured play observation.

The norm-referenced test will allow assessment of subjects that will produce developmental age (DA) and developmental quotient (DQ) scores. These scores indicate the average age at which 50% of the normative sample attained a particular score. For example, the normative sample population may have achieved a raw score of 50 by the time they were 24 months old. A child with a raw score of 50 would then have a developmental age of 24. The developmental quotient (DQ), which is the developmental age divided by the chronological age, indicates whether a child's developmental age matches the chronological age. Such scores are often used to estimate the severity of a child's delay.

A curriculum-based assessment focuses on the child's functional development and measures the degree of functional ability rather than assigning any particular developmental age. Bricker describes the benefits of using curriculum-based assessment such as Assessment, Evaluation, and Programming System for Infants and Children (AEPS), Volumes 1 and 2 [D. Bricker (Vol. 1); J. Cripe, K. Slentz and D. Bricker (Vol. 2), 1993)].

> The AEPS test does not provide norms for test outcomes. Although this may seem to be a disadvantage, norms have been eliminated so that the focus of intervention is on assisting children to acquire functional skills in a logical order, rather than on targeting items because they reflect the child's chronological age. For children with disabilities, the value of comparisons with developmental norms is, at best, questionnable (Bricker, 1996).

Two basic types of observation methods are structured observation and non-structured observation. Structured observation generally refers to defined procedures for collecting desired data. Non-structured observation generally refers to observing children and families without any defined procedures. Both types of observations can take place in the home or a professional setting, though structured observation may rely on clinical settings if the procedure requires the use of certain items such as specific toys and settings. It is generally thought that "there is no substitute for observations in real-life situations" (Bagnato et al., 1997; Odom and Shuster, 1986) and that "observation in a child's usual settings offers perhaps the best information" (Bagnato et al., 1997). For various reasons (e.g. parent discomfort) observing in a home setting is not always possible. Child developmental skills will be measured by unstructured play observation, as there is increasing recognition that "the developmental status of an infant or toddler can be assessed most effectively through spontaneous play" (Segal and Webber, 1996). If possible, observation should take place in the home.

Instrument sensitivity is an issue with indicators for the outcome domain, readiness to learn. While there are standardized tests that capture some of the elements of these indicators, they are limited as these elements have been less extensively studied than others (Hauser-Cram and Shonkoff, 1988). Readiness to learn indicators will be measured by both structured and unstructured play observations. Structured observations will focus on the indicators and devise processes to capture these indicators. It will most likely take place in a clinical setting. Unstructured play observation will be used to assess whether or not the readiness to learn indicators occur regularly in the child's usual settings.

Parent-child interaction will also be measured by unstructured and structured observation. With the increasing recognition of the importance of child-parent interaction (Kelly and Barnard, in press), there have been numerous observation scales designed specifically for this interaction [such as *Nursing Child Assessment Teaching Scale* (NCATS) (Barnard, 1978; Barnard et al., 1989; Barnard and Kelly, 1990)]. It is suggested that a standardized scale be used, supplemented with unstructured observation to gain information regarding the child-parent interaction not present in the structured observation criteria.

CHILD OUTCOMES, INDICATORS, AND DATA SOURCES

Child Outcomes	Data Source
1) Developmental Skills a. cognitive development b. communication c. social competence (social/emotional) d. adaptive (level of independence) e. physical (motor, visions, hearing)	Norm-referenced and Curriculum-referenced Standardized Tests (e.g *Bayley Scales of Infant Development* and *Assessment, Evaluation, and Programming System for Infants and Children*) Unstructured Observation

Child Outcomes	Data Source
2) Health a. children have the best possible health	Standardized Lists [e.g. *General Health Ratings Index* (Eisen et al., 1980)]
3) Readiness to Learn a. confidence b. curiosity c. persistence d. capacity to communicate e. capacity to get along with others	Unstructured Observation Structured Observation (e.g. *Nursing Child Assessment Teaching Scale*)
4) Child-Parent Interaction	Unstructured Observation Structured Observation

Family Outcomes and Measures

Selected family outcomes are knowledge, empowerment, parent-child interaction, and support. Indicators for knowledge are knowledge of child's disability, understanding what the child needs to enhance development, and the ability to read the child's cues. The three indicators chosen for empowerment are confidence in ability to enhance the child's development, confidence in the ability to interact with professionals and advocate for services, and locus of control (perception of self-empowerment). Indicators for parent-child interaction are responsivity and reciprocity. For the outcome, family support, the indicators of support will be examined (for a description of outcomes and indicators see Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter).

Measuring family outcomes will occur through a parent interview and through observation. All four outcomes will be measured through interviews with parents. Questions could include those developed by the National Early Intervention Longitudinal Study (see Chapter 3) such as *"Did early intervention enhance the family's perceived ability to work with professionals and advocate for service?"* (Bailey et al., 1998) or *"Did early intervention enable the family to help their child grow, learn, and develop?"*

Knowledge and parent-child interaction could be measured by structured observation scales, such as *Parent Behavior Progression* (Bromwich, 1983) or the *Nursing Child Assessment Teaching Scale* (NCATS) (Barnard, 1978; Barnard et al., 1989; Barnard and Kelly, 1990), to assess parent enjoyment of the infant, parent's sensitivity to the child's cues, development of parent skills in increasing the child's development, and other aspects of parent-child interaction. The tests mentioned have been developed for use with

populations of children with disabling or delaying conditions and their families (Barnard and Kelly, 1990). Unstructured observation will be used to assess knowledge and parent-child interaction to provide information undiscovered by the structured observation scales.

The parent interview will provide supplementary information for the outcomes knowledge and parent-child interaction, and primary information for the outcomes of empowerment and support. The interview will be semi-structured in order to cover designated indicators, but open-ended enough to gain descriptive insight into the early intervention experience for children and families.

FAMILY OUTCOMES, INDICATORS, AND DATA SOURCES

Family Outcomes	Data Sources
1) Knowledge a. knowledge of child's disability b. understanding what the child needs to enhance development c. ability to read child's cues	Parent Interview Structured Observation Unstructured Observation
2) Empowerment a. confidence in ability to enhance child's development b. confidence in ability to interact with professionals and advocate for services c. locus of control (perception of self-empowerment)	Parent Interview
3) Parent-Child Interaction a. responsivity b. reciprocity	Parent Interview Structured Observation Unstructured Observation
4) Support a. family has economic resources b. family has social support	Parent Interview

Case Studies

A small number (e.g. five to ten subjects) of the study sample will be chosen for case studies. Case studies provide descriptive information that provide depth and context to other assessment techniques. Material for case studies can be gathered from the data sources previously discussed, and from more open-ended methods such as unstructured interviews and observations. The greatest strength of case studies is that they provide the stories behind the data and convey contextual meaning to more quantitative data.

Data Collection

Tests will be conducted by both the research team and program staff who usually work with the child and family. While some precision may be lost in that the same testers will not be administering the assessments, participant responsiveness, especially with infants and toddlers is increased when working with someone they already know (Personal Interview, Maryanne Barnes, executive director, Tacoma Learning Center, 3/24/98). Interviews and observations will be conducted by trained research staff. Any assessment can be rescheduled per parent request. The study will track from birth to three years. T_1=within 8 weeks after provider notification. T_2 at 1 year after T_1; T_3 at exit of birth to three services.

An annual review of Individualized Family Service Plans (IFSPs) and records will take place to gather descriptive information regarding child and family progress. The aim of the review would be to track the:

a. Correspondence of Services to Parent Choice
b. Developmental Progress of Child

Parent choice may or may not be a prominent part of Individualized Family Service Plans. Since the purpose of the review of IFSPs and records is to provide descriptive information, data regarding whether or not services correspond to family choice can be obtained using information from the program observation and parent interviews as well as records information.

Similarly, the Individualized Family Service Plans (IFSPs) will reflect outcomes that the child and family have accomplished. Records information can be used to provide another method to view child development along with test, interview, observation, and case study data.

Individualized Family Service Plans (IFSPs) could also be reviewed to note whether they reflect comprehensive, coordinated, family centered, and culturally sensitive services—elements which reflect the aim of federal legislation with regard to early intervention services for children with disabling or delaying conditions and their families.

Data Analysis Methods

1) Test Outcomes (e.g. Proportional Change Index, Growth Curve Analysis)

Residual Change Scores for interval scores will be used. These scores compare predicted change scores to actual change scores. The predicted scores are calculated applying a regression equation which uses the following: a) individual's pre-test score b) distribution of sample score at T_1 c) relation between T_1 score and T_2 score for the entire sample (slope of regression) and d) distribution of scores at T_2. The residual change score is the difference between the individual's actual and predicted score. Its main use is to compare the degree a child and family have changed within the context of the study group. Other statistical methods, such as Growth Curve Analysis, are available and should be considered

when the research project is finalized. Different statistical models offer various strengths. For instance, Growth Curve Analysis is prevalent in research studies and is thought to provide a more accurate predicted score than other models (see Hatton et al., 1997). The Residual Change Score model can accommodate a greater variety of assessment measures than Growth Curve Analysis. Once the selection of outcome measures and instruments are finalized, researchers should carefully review these models. (For a summary of predicated change score statistical models see Appendix E.)

The Change Score Model also will be used. This model is often referred to as *simple change score*—which indicates that a straight comparison between scores taken at different times will occur. Assessments which do not have interval scores will use the change score model only. The main purpose of this model is to measure how *each* child and family changed. While this model has statistical drawbacks (see Weaknesses), it does offer a view to child progress that does not rely on the performance of the group as a whole.

2) Multivariate Analysis (multiple regression, partial correlation, etc.)

Multiple regression will be used. Multiple regression is a statistical procedure for understanding the simultaneous effects of one or more characteristics (independent variables) on a dependent variable (early intervention). Its main use will be to analyze how various child, family, and program characteristics affected outcomes.

3) Qualitative analysis

Results from the interviews and unstructured observations will be coded systematically. Some of the data will be presented in summary descriptive form. Other data will be quantified and can be used to draw general conclusions (e.g. 90 percent of families interviewed felt professionals respected their choices), or can be used to generate change scores.

TIMELINE

The total time estimated for the study is 3.5 years.

TIMELINE FOR SMALL SCALE LONGITUDINAL STUDY

STUDY YEAR	1	2	3	4
Age of Year 1 Subjects	.5-3 years	1.5-4 years		
Age of Year 2 Subjects		.5-3 years	1.5-4 years	
Organize Study*	X			
Recruitment	X	X		
Assessments		X	X	
Completed Report				X

* (hire staff, Human Research Review Board, establish criteria, establish recruiting sites)

DIRECT COST ELEMENTS

Cost estimates include only the direct costs of conducting the study. Indirect cost rates (to cover organizational overhead) vary widely depending on the type of organization, such as university, for-profit research center, or state agency. Depending on the specific indirect cost rate, indirect costs may represent 10 to 60 percent, or more, of the direct costs. With additional expenses for rent or lease for project space and indirect costs, total costs (direct plus indirect) could be **double** the estimated direct costs presented.

This study will incur the following direct cost elements:

* Participant Payment—subjects and service providers will be reimbursed for their time/effort in participation of the study
* Research Staff
* Supplies/Equipment
* Other (e.g. travel, postage)

TOTAL ESTIMATED DIRECT COST: $1,400,000

ISSUES

General Issues

Consideration should be given to the general issues mentioned in the previous study, Child/Family Serves as Own Control—Large Scale Longitudinal Study.

Strengths

Strengths of the smaller scale study are similar to those of the larger scale study and will not be discussed again in this section. For a review of the general strengths of the design refer to the Strengths section in the previous study.

The greatest strength of this study is that it provides both qualitative and quantitative data. Given the concerns regarding standardized instruments (see Methodological Challenges in this chapter), researchers have stressed the importance of using a variety of measurement techniques. Through a triangulation of measurement, results from both qualitative and quantitative inquiries can be drawn together to make well-grounded conclusions. This study uses normative and curriculum-based assessment (for a definition of terms see Methodological Challenges in this chapter), as well as unstructured and structured observation and interviews. Case studies are also used to convey the full context of early intervention services. The use of such a variety of methods provides a comprehensive basis to describe and assess early intervention services.

Another strength of the study is that the records review allows an opportunity to make general observations regarding Part H goals of the federal legislation. Through a review of Individualized Family Service Plans (IFSPs) and records, researchers will be able to

note whether the plans reflect comprehensive, coordinated, family centered, and culturally sensitive services.

Weaknesses

The major problem with the design is the same as that of the larger study—conclusions drawn from quantitative data rely on predicted and simple change scores. Other problems, such as the ability to control for all characteristics (independent variables) also pertain to this study (for a full discussion of weaknesses see the Weaknesses section in Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter).

SUMMARY: STRENGTHS/WEAKNESSES/TIME/ESTIMATED DIRECT COST

Major Strengths:

- The study would allow determination of which program components work for which children/ families.
- The design takes into account the multiple variables influencing child and family outcomes.
- The design reflects current recommendations regarding early intervention research.

Major Weaknesses:

- Conclusions rely heavily on residual change score and change score models.

ESTIMATED DIRECT COST: **$1,400,000**

ESTIMATED COMPLETION TIME: **3.5 years**

COMPARISON GROUP—LONGITUDINAL STUDY

DESCRIPTION

This study will longitudinally compare those children and families who enrolled in early intervention, to those who qualified for services but chose not enroll.

PART I—Pre-outcome Study

- Service providers identify families who qualify for services but choose not to participate and establish whether or not they would be willing to receive information about the study.
- Researchers ascertain whether or not the families qualify for and agree to participate in the study.

PART II—Outcome Study

PHASE ONE

Child Outcomes: (1) Child-Parent Interaction (2) Developmental Skills (3) Health (4) Readiness to Learn

Family Outcomes: (1) Knowledge (2) Empowerment (3) Support (4) Parent-Child Interaction

PHASE TWO

Child Outcomes: (1) Child Relationships (2) Child Behavior (3) School Performance (4) Child's Service Status

Family Outcomes: (1) Transition Experience (2) Impact of Intervention

Methods

(1) Testing—Standardized Testing
(2) Survey of Parents (written or phone)
(3) Survey of Teacher/Service Provider
(4) Child and Family Observation
(5) Program Services Observation

Major Strengths:

- If enough subjects who qualify for early intervention, but do not enroll, participate in the study, this design will provide an opportunity to compare directly and comprehensively those who receive services to those who do not.

Major Weaknesses:

- Identifying a sufficient number of qualified, but not enrolled, subjects who are comparable to the target group might be difficult.
- Cooperation from qualified but non-enrolled families may be a problem.

ESTIMATED DIRECT COST:	**$4,000,000**
ESTIMATED COMPLETION TIME:	**12 years**

COMPARISON GROUP—LONGITUDINAL STUDY

SUMMARY

This study will examine the impact of early intervention on children with delaying or disabling conditions and their families in Washington State by comparing those children and families who enrolled in early intervention to those that qualified but did not enroll.

The study is divided into two parts. Part I will identify whether or not there is a sufficient comparison group willing to participate in the study. Part II will conduct a study similar in design to the larger scale longitudinal study (ages birth to eight) in which children serve as their own controls (for details of outcomes, indicators, and data collection methods see Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter).

INTRODUCTION

Research on the effectiveness of early intervention is hampered by the methodological problems generated by the lack of a control group. Since service in Washington is mandated for those children found eligible who accept enrollment, it is unethical and illegal to deny children treatment. If subjects cannot be randomly assigned to a control/treatment group, however, it is difficult to conclude that changes in child/family development are due strictly to early intervention.

Given the ethical complexities in establishing a control group, the next logical alternative is to isolate a comparison group who qualified for early intervention services, but chose not to enroll. Several problems face this approach as well. Since children and families are not randomly assigned, group comparability becomes a concern. In order to match groups on defining characteristics (such as type of disability, severity of condition, gender, etc.) a fair number of subjects would have to be recruited. It is also necessary to know *which* defining characteristics influence whether or not a family chooses to receive services. In order to carry out a longitudinal study that accounts for background characteristics (independent variables) of families, children, and programs, and which takes into consideration 30 percent attrition, approximately 260 subjects are needed. In this study the groups would be divided into those that chose to receive early intervention (n=130) and those who chose not to participate (n=130).

Possible Indications of Subject Numbers Available

In Washington, there is no compiled record of the number of children and families who qualified for services but chose not to enroll. Some numbers may be useful in estimating whether or not there is a possibility of recruiting 130 children and families who were eligible for enrollment but chose not to enroll. The following discussion pertains *only* to estimating whether or not there is a *possibility* for a comparison group of sufficient numbers. The groups of children identified below will *not* be considered as possible comparison groups. Identification of possible comparison subjects for the study will occur at service sites (see the subsequent section, Recruitment, for further details).

Infant Toddler Early Intervention Program Records

- The Infant Toddler Early Intervention Program (ITEIP) tracks the number of children who are eligible for ITEIP services and the number of children who have Individualized Family Service Plans (IFSPs). These numbers are reported from individual contractors. From October 1996-September 1997, 2,641 children were eligible for enrollment and 2,128 had IFSPs. While the difference (513) *could* represent those that qualified and did not enroll, many other reasons are possible. Such reasons may include the following: 1) some children may have been assessed in September 1997 but had not *yet* enrolled at the time of report; 2) some enrolled children and families may not have developed an IFSP at the time of the report; 3) although the child and family may be eligible for ITEIP, the majority of their care may be covered by a source not affiliated with the ITEIP; or 4) the families could have moved between the assessment date and the enrollment count. In sum, this number should not be used to estimate the number of qualified families who choose not to enroll in early intervention services.

Medicaid Records

- Medicaid records could possibly be used to indicate whether there is a potential subject pool who qualify but do not enroll for early intervention services. For example, from December 1993-December 1995, 94 Medicaid children were diagnosed with Down Syndrome, and 80 of these children were enrolled in early intervention services (Keenan et al., *Washington's Infant Toddler Early Intervention Program Study*, 1997). While one possible reason for the difference (14) could be that families of children with Down Syndrome decided not to enroll, other explanations are possible (if not probable). Figures could be due to the receipt of private services or the fact that a child and family may have moved by the time of the enrollment count, or the fact that a child might have died.

From these numbers it is difficult even to speculate whether the possibility of conducting a study with a large enough number of subjects to be statistically significant exists. The numbers do indicate, however, that there may be some families who choose not to enroll in services. Since estimates of possible subjects for the non-participation group are unavailable, the first step in the study would involve obtaining this number. If enough of a subject pool is available (n=130), groups will be stratified according to type and severity of delay.

METHODS PART I—LOCATING A COMPARISON GROUP

Eligibility

To be eligible for inclusion in the study, families must meet the following conditions: 1) they qualify for early intervention services but choose not to enroll, 2) they agree to be contacted by the research team, 3) they agree to participate in the study, and 3) they are not receiving *any* early intervention services (e.g. privately funded services).

Recruitment

Estimating how many children and their families qualify for early intervention services but do not enroll (because of choice), relies on the cooperation of contractors and service providers to monitor these numbers over a one year period and to estimate how many of these families would be willing to participate in the study. For this purpose the research team will need to provide a brief description of the study which explains its focus and purpose. Contractors and service providers will be responsible for: 1) noting which children and families qualify, but choose not to enroll, 2) ascertaining whether or not families would be willing to receive information regarding the study from researchers, 3) establishing whether or not the family is receiving private services, and 4) providing researchers with the names and addresses of eligible families after families consent. (Providers and contractors will be paid for their time.) Researchers will then contact willing, eligible families to establish a data collection schedule and to arrange confidentiality agreements.

Data Collection

Data on eligible non-enrollment subjects should be collected by researchers as soon as the subjects are recruited. Even if a sufficient number of subjects (n=130) are not recruited to complete the study, families who choose not to enroll their children in early intervention services provide an important perspective and can contribute valuable descriptive information (Presentation, Dr. Susan Janko, 2/6/98). If enough families are recruited, the study will continue.

PART II—OUTCOME STUDY

This part of the study is similar in structure to the Child/Family Serves as Own Control—Large Scale Longitudinal Study. Because there will be a comparison group, predicted change score and simple change score models will not be used, but rather results from the two comparison groups will be directly compared (for details see Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter). The discussion which follows concentrates on those elements of the studies that differ.

Eligibility Criteria

The target population is all birth to three children and their families newly enrolled in early intervention services in Washington State. Recruitment for enrolled participants will occur at the end of Part I (one year) if a sufficient number of subjects for the comparison groups has been identified.

Sample Size

The ideal size of the study, accounting for a 30 percent attrition rate over time, would be approximately 260 subjects (α=.05, statistical power is at .80, and effect is ~.33). The sample size will be divided as follows: n= 130, non-enrolled subjects; n=130 enrolled

subjects. Groups will be matched on disability (Down Syndrome, motor impairment, developmental delay), severity (moderate/severe), age, and gender.

Data Analysis

1) Test Outcomes

Direct comparison of scores will be used.

2) Group Comparability

Comparability will be measured using *t* tests. *T*-tests are used to calculate significant differences between comparison groups and to analyze whether these differences had statistically significant effects on the measured outcomes.

3) Multivariate Analysis

Multiple regression will be used to assess which services work best for which subjects who receive services. [Multiple regression is a statistical procedure for understanding the simultaneous effects of one or more characteristics (independent variables) on a dependent variable (early intervention).]

It should be noted that little research has been done that analyzes *why* some families choose service and others do not. Because of this gap in research knowledge, controlled characteristics in this type of study usually reflect those that are known to affect child and family development (Dihoff et al., 1994).

TIMELINE

The total time for the study is estimated at 12 years.

TIMELINE FOR COMPARISON GROUP—LONGITUDINAL STUDY

STUDY YEAR	1	2	3	4	5	6	7	8	9	10	11	12
Age of Year 2 Subjects		.5-3 yrs	1.5-4 yrs	2.5-5 yrs	3.5-6 yrs	4.5-7 yrs	5.5-8 yrs	6.5-9 yrs				
Age of Year 3 Subjects			.5-3 yrs	1.5-4 yrs	2.5-5 yrs	3.5-6 yrs	4.5-7 yrs	5.5-8 yrs	6.5-9 yrs			
Age of Year 4 Subjects				.5-3 yrs	1.5-4 yrs	2.5-5 yrs	3.5-6 yrs	4.5-7 yrs	5.5-8 yrs	6.5-9 yrs		
Organize Study*	X											
Recruit Part I		X	X	X								

STUDY YEAR	1	2	3	4	5	6	7	8	9	10	11	12
Recruit Part II			X	X								
Part II Phase I			X	X	X	X						
Part II Phase II				X	X	X	X	X	X	X		
Analysis Phase I							X					
Final Report											X	X

* (hire staff, Human Research Review Board, establish criteria, establish recruiting sites)

DIRECT COST ELEMENTS

Cost estimates include only the direct costs of conducting the study. Indirect cost rates (to cover organizational overhead) vary widely depending on the type of organization, such as university, for-profit research center, or state agency. Depending on the specific indirect cost rate, indirect costs may represent 10 to 60 percent, or more, of the direct costs. With additional expenses for rent or lease for project space and indirect costs, total costs (direct plus indirect) could be **double** the estimated direct costs presented.

This study will incur the following direct cost elements:

* Participant Payment—subjects and service providers will be reimbursed for their time/effort in participation of the study (Part I and Part II)
* Research Staff
* Supplies/Equipment
* Other (e.g. travel, postage)

TOTAL ESTIMATED DIRECT COST: $4,000,000

DISCUSSION

Due to the difficulties in locating a general comparison group, many studies using this methodology seek to evaluate the impact of a certain program component, such as Interaction Coaching (Seifer et al., 1991) or Parent Involvement (Agee, 1994) rather than assessing early intervention in general. In this way, researchers can still guarantee service (and so meet ethical requirements) yet can contribute to specific questions of service impact utilizing subject numbers that produce statistically significant results. Given this type of framework, however, studies are able to use randomization in assigning subjects to groups with extra elements of service components and to control groups without the extra element to produce more accurate results (Innocenti et al., 1993; Ramey et al., 1992; Taylor, 1993).

ISSUES

General Issues

Consideration should be given to the general issues mentioned in the Child/Family Serves as Own Control--Large Scale Longitudinal Study in this chapter.

Strengths

The greatest strength of this study is that it provides an actual comparison group who does not receive services. If a large enough comparison group exists (n=130), it would provide baseline outcome data against which to contrast target group (those that received services) data. If the comparison group could be matched on critical characteristics (see the section describing characteristics in Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter), conclusions could be made in regard to attributing changes in outcomes to early intervention.

Another strength of the study is the ability to track and compare groups longitudinally. Children and families will be monitored from enrollment in birth to three services until the child is seven years old, which provides an opportunity to assess directly the long-term benefits of early intervention.

Weaknesses

The major weakness with the design is that it is possible that researchers will be unable to recruit sufficient numbers of those children and families who: 1) qualified for services but choose not to enroll, 2) will cooperate, and 3) are not receiving any other early intervention services. The likelihood of families who decline services participating in a ten to twelve year evaluative study is questionable.

Group comparability is also a concern. Since children should be matched, at the very least, on type and severity of delay, generating a group of comparable children may be problematic. Similarly, the reasons for refusal of services are not widely known, making it difficult for researchers to control for group distinctions on this basis. While possible explanations such as health reasons, religious reasons, level of education, U.S. legal residence status, and poverty status could be proposed, there have not been enough studies to assess the validity of such constructions. The impact of these factors on child development should be assessed in order to strengthened conclusions regarding whether or not changes in outcomes can be attributed to early intervention services.

Another consideration involves the commitment of time and resources to a research project that may be suspended after Part One due to insufficient subject numbers. Funding should be obtained for the entire study before it actually commences. If it were discovered in Part One that a large enough comparison group could not be recruited, Part Two of the project could not commence. While funding could be obtained one part at a time, delays in funding of Part Two of the study would create methodological problems with testing

procedures in that many subjects would be older than originally anticipated. In sum, funding issues may be problematic.

SUMMARY: STRENGTHS/WEAKNESSES/TIME/ESTIMATED DIRECT COST

Major Strengths:

- The greatest strength of this study is that it provides an actual comparison group which does not receive services.
- The study allows comprehensive longitudinal assessment.

Major Weaknesses:

- The major weakness with the design is that it is possible that researchers will be unable to recruit sufficient numbers of non-enrolled children and families who are willing to cooperate.
- Group comparability is a concern.

ESTIMATED DIRECT COST:	**$4,000,000**
ESTIMATED COMPLETION TIME:	**12 years**

PRE-POST STUDY

DESCRIPTION

This study will compare profile information of those children and families who enrolled in early intervention in 1993, to those who enrolled in 1997. Families of the groups will be surveyed for information regarding impressions of service delivery and impact.

PROFILES

Create profiles of children enrolled in early intervention in 1993 and 1997.

Profile Data

Infant death, Child death, Accepted referral to Child and Protective Services, Placement by Children's Services out-of-home, Divorce, Parent Employment

Medicaid Only

Child hospitalization, Medicaid infant costs, Diagnosed medical condition Medicaid and grant eligibility

Methods

(1) State data bases

OUTCOMES

(1) General Impact of Early Intervention on Child/Family
(2) Perception of Services

Methods

(1) Survey of Parents (written)

Major Strengths:

- The study would provide descriptive profile data for enrolled children.
- The study allows comparison of pre- and post-Part H full implementation time periods.

Major Weaknesses:

- Since Part H was phased in from 1991-1994 and full implementation occurred in different time frames depending on geographic location, the pre/post time periods are not precise.
- Outcome measures would be restricted to those that can be measured by the survey.
- Since types of services received rely solely on the memory of parents, attributing changes in outcomes strictly to early intervention is problematic.

ESTIMATED DIRECT COST:	**$385,000**
ESTIMATED COMPLETION TIME:	**1.5 years**

PRE-POST STUDY

SUMMARY

This study compares the profile information of children under the age of three who were enrolled in early intervention services in 1993 to the profile information of children enrolled in 1997. To supplement the comparison of profile information available from state data systems, a questionnaire will be sent to a sample of parents whose children are in the study groups. The study will assess parent perception of early intervention services before full implementation of Part H and after.

INTRODUCTION

Part H of the Federal Individuals with Disabilities and Education Act (IDEA) was designed to improve the coordination of services among programs serving infants and toddlers with disabilities, to ensure the availability of comprehensive services in all localities, and to ensure services are more family centered. This program was phased in (1991-1994) after a five year planning period (1987-1991) in Washington State with full implementation occurring in October 1994. The purpose of this study is to compare parent perception of the impact of early intervention on their children and their perception of services in 1993 and 1997, and assess differences in child and family profiles of the comparison groups.

PROFILES

Methods

The Department of Social and Health Services (DSHS) is the designated lead agency for administration of Part H. The Infant Toddler Early Intervention Program, DSHS contracted with Research and Data Analysis to conduct counts of children enrolled in publicly funded programs providing early intervention services in December 1993, May 1995, December 1995, May 1996, December 1996, and December 1997. Children enrolled in early intervention services in December 1993 began services prior to the full implementation of Part H. The count done by Research and Data Analysis of children enrolled in December 1993 will be used as the *pre* group. The December 1997 count will be used for the *post* group.

This study will draw on data in the First Steps Database. The First Steps Database contains information from birth certificates and Medicaid claims for children born to Washington residents from 1988 through 1997 (pending at this time). Children enrolled in early intervention services who were not born to Washington residents will not be included. This number amounts to approximately 15 percent of all children enrolled in publicly funded early intervention services (Keenan et al., 1996; Keenan et al., 1997). The First Steps Database will provide critical information on child and parent profile information and will help to identify other key data through linkage to other systems including referral to Child and Protective Services, out-of-home placement and foster care, parents' wages before and after delivery, child death, and child and parent welfare

eligibility after delivery. Profiles will be completed for all children in the First Steps Database.

Profile Information

For all children in the First Steps Database the following information is available from existing state data systems:

DATA AVAILABLE FOR ALL CHILDREN IN THE FIRST STEPS DATABASE

DATA	DATA SOURCE
Infant death	FSDB*
Child death	DOH-CHS**
Accepted referral to Child and Protective Services	CAMIS***
Placement by Children's Services out-of-home	CAMIS***
Divorce	DOH-CHS**
Parent Employment	ESD+

* First Steps Database
** Department of Health—Center for Health Statistics
*** Case and Management Information System
\+ Employment Security Department

For all children with Medicaid claims in the First Steps Database the following additional information is obtainable:

DATA AVAILABLE FOR ALL CHILDREN WITH MEDICAID CLAIMS IN THE FIRST STEPS DATABASE

DATA	DATA SOURCE
Child hospitalization, Medicaid infant costs	FSDB*
Diagnosed medical condition	
Medicaid and grant eligibility	OFM**

* First Steps Database
** Office of Financial Management

It should be noted that Medicaid records will not be available for children who were ages 2 to 3 years in 1993. Also, those children in Healthy Options will not have fee-for-service Medicaid records.

OUTCOMES

A retrospective questionnaire will be sent to the parents of children who were enrolled in early intervention programs in 1993 and 1997 after obtaining consent from the parents and passing requirements of the Human Research Review Board. Such questions pertaining to types of services offered and received, the amount of service coordination, and transition into Part B experiences could be asked. Questions could also be asked regarding parent perception of the general impact of early intervention on their children and the family. Given the objectives of Part H in regard to service delivery, this survey would provide direct information for both the *pre* and *post* group on their perception of services. It would also allow a comparison of the impressions of parents whose children's ages are separated by four years with regard to the impact of early intervention programs. Because of the cost of surveying all enrolled children, it will be necessary to develop a sampling strategy limiting the sample size to 1,000 for each of the pre- and post- periods.

The following outcome information will be obtained for the sample of children in the parent survey:

OUTCOMES AND SAMPLE SURVEY QUESTIONS

OUTCOME	SAMPLE QUESTION
Child Outcomes:	
1) Impact on Child From Early Intervention	*Did early intervention make a difference in your child's life?* (Bailey et al., 1998)
Family Outcomes:	
1) Impact on Family from Early Intervention	*Did early intervention assist you in building a strong support system?* *Did early intervention enable you to help your child grow, learn and develop?* (Bailey et al., 1998)
Services	
1) Availability 2) Accessibility 3) Description of Services Which services? How often? Family centered?	*Did you feel services were family centered?*

Sample Selection

The 1,000 subject sample from each group (1993 and 1997) will be randomly selected from families and children on the First Steps Database who were enrolled in early intervention.

TIMELINE

The total time for the study is estimated at 1.5 years.

TIMELINE FOR PRE-POST STUDY

TASKS	5 mos	1 yr	1.5 yrs
Design retrospective survey with input from programs	X		
Submit proposal to HRRB* for pre/post comparison study			
Collection of additional data sources such as employment security and Medicaid claims			
Processing of CAMIS** and child death data			
Obtain cooperation from programs for retrospective survey			
Submit proposal to HRRB* for retrospective survey			
Obtain HRRB* approval for retrospective survey			
Pre-test survey			
Develop current address file			
Data analysis for profiles			
Obtain passive consent from parents for retrospective survey		X	
Send retrospective survey			
Report writing for profiles			
Follow-up of retrospective survey			
Telephone follow-up			
Data analysis of retrospective survey			
Report writing of retrospective survey			X

* Human Research Review Board
** Case and Management Information System

DIRECT COST ELEMENTS

Cost estimates include only the direct costs of conducting the study. Indirect cost rates (to cover organizational overhead) vary widely depending on the type of organization, such as university, for-profit research center, or state agency. Depending on the specific indirect cost rate, indirect costs may represent 10 to 60 percent, or more, of the direct costs. With additional expenses for rent or lease for project space and indirect costs, total costs (direct plus indirect) could be **double** the estimated direct costs presented.

This study will incur the following direct cost elements:

* Participant Payment—subjects and service providers will be reimbursed for their time/effort in participation of the study
* Research Staff
* Supplies/Equipment
* Other (e.g. travel, postage)

TOTAL ESTIMATED DIRECT COST: $385,000

DISCUSSION

While much information is available from state data systems, a retrospective survey of a sample of children and their families who received birth to three services in 1993 and 1997 will provide information regarding their impressions of impact and services during these time periods. The survey will ask about type of disability or delay, identification of disabilities, referral to services, initial services received, intensity and type of services received, whether or not services were coordinated and family centered, and current child development. The survey will require cooperation from programs and approval from the Human Research Review Board.

Studies indicate a high level of reliability for many questions related to infants with disabilities when asked at different points in time. Parents respond to questions such as when they first recognized their child's disability or delay, who first diagnosed their child's disability or delay, and when they first received early intervention services similarly when their child is young as when their child is grown (Carr, 1987; Palfrey, 1987).

ISSUES

Strengths

The greatest strength of this study is that it provides comparison groups of pre-Part H full implementation and post-Part H full implementation time periods. While these dates do not accurately reflect a true pre- and post- time period (see Weaknesses), the study would provide interesting information regarding how parents perceived services and their benefits in 1993 and 1997. If the study were to take place in 1999, the children who participated in early intervention in 1993 would be 6 to 9 years old; and those who participated in 1997 would be 2 to 5 years old. The study would allow the contrast of parent feedback whose

children are still in early intervention or have recently transitioned, to those parents whose children are substantially older. The study may also provide insight into how services might have changed during those four years.

Detailed profiles would be established for a majority of the children enrolled in 1993 and 1997 and provide information that previously has been undisclosed. The profiles would use information already present in state data bases and provide a full description of many children with disabling or delaying conditions and their families using publicly funded early intervention services in Washington State. Information such as infant and child death, placement in foster care, and parent employment would contribute to the understanding of the possible needs of those who are being served in the state.

Other strengths of the study are that it is relatively inexpensive and can be completed in under two years, and it has a large subject number which increases the generalizability of results.

Weaknesses

One major weakness of the study is that child and family outcomes are restricted to information that can be obtained through the parent survey. The survey will ask parents about how early intervention impacted their children and families, and inquire about service delivery. While the information provided by parents will be interesting and useful, because the description of services cannot be verified and relies strictly on the memory of parents, concluding that the impact parents describe is strictly due to intervention is problematic.

Another concern with the study is that there is no clear demarcation between pre- and post-Part H since the program was phased in over a number of years and its full implementation varied from location to location. In 1993, Part H had been phased in since 1991 indicating that some areas probably achieved close to full implementation as early as 1993. The changes that took place in services between 1993-1997 such as coordination, family focus, and the use of Family Resource Coordinators (FRCs) may not be reflected in the surveys. Although data on whether or not families had FRCs is available, people working in the field have remarked that families refer to their FRC by name and often do not remember their position title (Advisory Group Meeting, 5/15/98); and given that some will have been out of services for four or more years, parents may not remember details that would allow conclusions to be drawn regarding changes in services. Results from the study should be treated as providing primarily descriptive information regarding how parent perceptions differ during these time periods.

One other weakness of the study is that a possible selection bias may exist in that those families who are unable to be reached cannot participate in the study. The selection bias will detract from the generalizability of the results.

SUMMARY: STRENGTHS/WEAKNESSES/TIME/ESTIMATED DIRECT COST

Major Strengths:

- The study would provide descriptive profile data for enrolled children.
- The study allows comparison of pre- and post-Part H full implementation time periods.

Major Weaknesses:

- Since Part H was phased in from 1991-1994 and full implementation occurred in different time frames depending on geographic location, the pre- and post- time periods are not precise.
- Outcome measures would be restricted to those that can be measured by the survey.
- Since types of services received rely solely on the memory of parents, attributing changes in outcomes strictly to early intervention is problematic.

ESTIMATED DIRECT COST: **$385,000**

ESTIMATED COMPLETION TIME: **1.5 years**

RETROSPECTIVE CROSS-SECTIONAL STUDY

DESCRIPTION

This study will analyze early intervention programs for birth to three year olds by looking at children enrolled in programs for older children (ages three to six). A group of those who had birth to three early intervention will be compared to a group of those who perhaps should have received birth to three services, but did not.

PART I—THREE TO SIX COUNT

Conduct three to six count.

PART II—DETERMINATION OF COMPARISON GROUP

Sample three to six population who did not receive early intervention. Determine which subjects of this sample were likely to have qualified for birth to three, but were not identified or did not enroll.

Methods

(1) Retrospective survey
(2) Medicaid claim forms

PART III—PROFILES

Create profiles of the two comparison groups.

Profile Data

Infant death, Child death, Accepted referral to Child and Protective Services, Placement by Children's Services out-of-home, Divorce, Parent employment

Medicaid Only

Child hospitalization , Medicaid infant costs, Diagnosed medical condition Medicaid and grant eligibility

Methods

(1) State data bases

PART IV—OUTCOMES

Child Outcomes: (1) Developmental Skills
(2) Health
(3) Readiness to Learn
(4) Child Relationships

For Those That Received Services:
(5) Description of Impact of Early Intervention on Child/Family
(6) Description of Services

Family Outcomes: (1) Knowledge (2) Empowerment

Methods

(1) Survey of Parents (phone/written)
(2) Observation
(3) Standardized Tests
(4) Records Review

Strengths:

- The study will provide a comparison group.
- The study will possibly reveal which groups of infants and toddlers are under-served.

Major Weaknesses:

- It will be difficult to determine which children should have received early intervention services before the age of three.
- Attributing differences in assessment scores solely to receipt of birth to three services is problematic.
- Group comparability is an issue.

ESTIMATED DIRECT COST:	**$715,000**
ESTIMATED COMPLETION TIME:	**2.5 years**

RETROSPECTIVE CROSS-SECTIONAL STUDY

SUMMARY

This is a retrospective study of children in publicly funded programs for those aged three to six years with delaying or disabling conditions. Their enrollment in programs prior to turning three will be determined. A retrospective parent survey will be conducted for a sample of children who were not enrolled in birth to three services in order to ascertain whether or not their children might have qualified for birth to three services. Those children and families that were likely to qualify for birth to three services, but did not enroll (and were not receiving other privately funded services), will be compared to those children and families enrolled in three to six programs who *were* previously enrolled in birth to three services. A survey regarding parent perception of birth to three services will be conducted.

INTRODUCTION

The study will compare children in programs for three to six year olds based on their prior enrollment in programs for birth to three year olds. The identification of these two groups—children with and without prior enrollment in birth to three programs—will permit comparison of the types of children served in these two age categories, comparison of child and family outcomes, analysis of the transitioning of children from early intervention programs for the younger age group into programs for three to six year olds, and identification of under-served or under-identified children.

PART I—ENROLLMENT COUNT

METHODS

Three to Six Count

A count of children with disabling or delaying conditions enrolled in programs for three to six year olds will be conducted. The basic component of this part of the study is a listing of children from ages three to six enrolled in Washington State public services for those with disabling or delaying conditions. This listing, a snapshot in time of the population enrolled in three to six programs, will be obtained by surveying service providers. Prior to the date of the count, surveys will be mailed to providers of preschool services. The survey will request a list of every child from ages three to six who was enrolled with the provider on the day of the count. Duplicated counts (children receiving services from more than one provider) will be eliminated through an unduplication process. Records belonging to the same child can be identified using last name, middle name, first name, gender, and date of birth. Human Research Review Board (HRRB) review and an agreement with Office of Superintendent of Public Instruction (OSPI) are required to conduct the count in order to conform with rules regarding confidentiality concerns.

Identification of Those Who Received Birth to Three Services

The three to six count data will be combined with the information from Department of Social and Health Services, Research and Data Analysis' enrollment counts in early intervention programs for children under age three in December 1993, December 1995, December 1996, and December 1997. This cross-comparison can determine whether children and families in the three to six count were enrolled in birth to three services.

The following table displays the age of the children in the various December counts conducted by Research and Data Analysis (RDA). It can be used to understand how the information from enrollment counts in the two programs can be used to develop study groups.

AGE OF CHILDREN IN RDA ENROLLMENT COUNTS FOR BIRTH TO THREE PROGRAM

1993	1994	1995	1996	1997	1998	1999	2000
Dec count	1-4	2-5	3-6	4-7	**5-8**	6-9	7-10
		Dec count	1-4	2-5	**3-6**	4-7	5-8
			Dec count	1-4	**2-5**	3-6	4-7
				Dec count	**1-4**	2-5	3-6

For example, if a count of children served by programs for three to six year olds were conducted in December 1998, it would be possible to examine their enrollment in programs for under three year olds using the December 1993, December 1995, December 1996, and December 1997 counts. Two main study groups could be identified: 1) children enrolled in three to six programs with prior enrollment in birth to three programs; and 2) children enrolled in three to six programs without prior enrollment in birth to three programs.

PART II—DETERMINATION OF COMPARISON GROUP

METHODS

The early intervention program for three to six year olds enrolls many more children than the program for children under age three. Enrollment for children under three is about 5,000 while approximately 12,000 children aged three to six are enrolled in programs for children with disabling or delaying conditions (Office of Superintendent of Public Instruction (OSPI), 1997). Many factors change as a child grows older, most especially the number of contacts with professionals (school, day care, doctors) and the obviousness of many types of developmental disability and delay. Illness or accidents will also result in some children acquiring new disabilities. The group of greatest interest will be the children with a disability or delay which likely made them eligible for birth to three services but who were not enrolled in intervention programs until they were older.

A retrospective questionnaire will be sent to a random sample of 1,000 parents of children enrolled in three to six programs who were not enrolled in early intervention. Parents will be contacted only after their consent is obtained (via passive consent forms). This survey, combined with Medicaid claim data for some children, will be used to determine type and severity of disability or delay and eligibility for services before the age of three. The current degree of delay will also be helpful in estimating whether or not children should have received birth to three services. The survey will inquire as to whether or not children received private intervention services. From the initial 1,000 sampled, it is expected that many will not qualify for the comparison group. Examples of reasons for exclusions could include the following: 1) parents were unaware of any delays until the age of three, 2) parents and child were receiving other intervention services, or 3) child was not diagnosed with any delays until three. Examples of reasons for inclusion in the study include the following: 1) child was diagnosed with a delay but was not referred to intervention services, or 2) child was diagnosed with delay but parents/healthcare providers did not enroll for any services.

PART III—PROFILES

Similar to the Pre-Post Study, profiles on the two groups can be created using state data banks. Review tables follow.

PROFILE DATA AVAILABLE FOR CHILDREN ENROLLED IN PUBLICLY FUNDED SERVICES

DATA	DATA SOURCE
Infant death	FSDB*
Child death	DOH-CHS**
Accepted referral to Child and Protective Services	CAMIS***
Placement by Children's Services out-of-home	CAMIS***
Divorce	DOH-CHS**
Parent Employment	ESD+
Child hospitalization, Medicaid infant costs	*Medicaid only*
Diagnosed medical condition	FSDB*
Medicaid and grant eligibility	*Medicaid only*
	OFM++

It should be noted that Medicaid records will not be available for children who were ages 2 to 3 years in 1993. Also, those children in Healthy Options will not have fee-for-service Medicaid records.

* First Steps Database
** Department of Health—Center for Health Statistics
*** Case and Management Information System
\+ Employment Security Department
++ Office of Financial Management

PART IV—OUTCOMES

METHODS

To assess child and family outcomes, two methods will be used. A survey similar to the Pre-Post Study will be sent to parents of children enrolled in three to six programs who were previously enrolled in birth to three. The survey will ask questions regarding impact of services on the child, family benefits, and service provisions (including transition experience). A records review will be included as part of this survey to track which services parents and children actually did receive.

The second method will involve sub-groups of the two comparison groups. Observation and standardized tests will be used to assess the children (who are now enrolled in three to six programs) and their families. The study is cross-sectional and will measure data at one point in time.

Recruitment of Children and Families

Families who agree to be part of the study (using passive consent) will form selection pools (one for each group). From this pool, participants will be selected randomly.

Sample Size

For the survey of parents whose children were enrolled in three to six programs who were previously enrolled in birth to three programs the sample size will be 1,000. For the observation and standardized assessments each group will contain 100 subjects: n=100 (previously enrolled in birth to three), n=100 (not previously enrolled).

Observation and Standardized Assessment

Child Outcomes and Measures

Child outcome assessment will occur in four domains: 1) Developmental Skills, 2) Health, 3) Readiness to Learn, and 4) Child Relationships. The same indicators as explained previously in the study, Child/Family Serves as Own Control—Large Scale Longitudinal Study will be used for the outcomes. The outcome, Child Relationships will use the indicator peer group interaction as the children are older and interrelate more with peer groups than the birth to three population.

Child Development will be measured by standardized tests [e.g. *Bayley Scales of Infant Development* (Bayley, 2nd edition, 1993) or *Battelle Developmental Inventory* (BDI) (Newborg et al., 1984)]. Health will be measured by a standardized checklist. Readiness to Learn indicators will be measured by structured and unstructured observation (for a discussion of observation see Child/Family Serves as Own Control—Small Scale Longitudinal Study in this chapter). Relationships will be measured by a non-standardized observational scale developed by Washington State University, Inclusion Education Research Project (Peck et al., 1992).

CHILD OUTCOMES, INDICATORS AND DATA SOURCES FOR THE RETROSPECTIVE CROSS-SECTIONAL STUDY

Child Outcomes	Data Source
1) Developmental Skills a. cognitive development b. communication c. social competence (social/emotional) d. adaptive (level of independence) e. physical (motor, vision, hearing)	Standardized Test [e.g. *Bayley Scales of Infant Development* (Bayley, 2nd edition, 1993) or *Battelle Developmental Inventory* (BDI) (Newborg et al., 1984)]
2) Health	Standardized Checklist [e.g. *General Health Rating Index* (Eisen et al., 1980)]
3) Readiness to Learn a. confidence b. curiosity c. persistence d. capacity to communicate e. capacity to get along with others	Structured and Non-structured Observation
4) Relationships a. child-peer interaction	Non-standardized Observation Scale [e.g. *Inclusion Outcomes Rating Scale* (Peck et al., 1992)]

Family Outcomes and Measures

Family outcome measures will include knowledge and empowerment. The three indicators for knowledge are the following: 1) knowledge of child's disability, 2) understanding what the child needs to enhance development, and 3) ability to read their child's cues. The three indicators chosen for empowerment are the following:

1) confidence in ability to enhance child's development, 2) confidence in ability to interact with professionals and advocate for services, and 3) locus of control (perception of self-empowerment) (see Child/Family Serves as Own Control—Large Scale Study in this chapter for a discussion of these outcomes and indicators).

Measuring knowledge and empowerment will occur through standardized self-assessment tools [such as *Parent Self-awareness Scale* (Snyder et al., 1985), *Child Improvement Locus of Control Scales* (Devellis et al., 1985)] and structured observation [such as *Parent Behavior Progression* (Bromwich, 1983)].

FAMILY OUTCOMES, INDICATORS AND DATA SOURCES FOR THE RETROSPECTIVE CROSS-SECTIONAL STUDY

Family Outcomes	Data Source
1) Knowledge a. knowledge of child's disability b. understanding what the child needs to enhance development c. ability to read child's cues	Structured Observation [e.g. *Parent Behavior Progression* (Bromwich, 1983)]
2) Empowerment a. confidence in ability to enhance child's development b. confidence in ability to interact with professionals and advocate for services c. locus of control (perception of self-empowerment)	Standardized Self-assessment [e.g. *Parent Self-awareness Scale* (Snyder et al., 1985), *Child Improvement Locus of Control Scales* (Devellis et al., 1985)]

Data Collection

Data collection will take place at one time 2 years after the study is initiated.

Data Analysis Methods

1) Test Outcomes

Direct comparison of scores will be used.

2) Group Comparability

Comparability will be measured using *t* tests. *T*-tests are used with data measured on an interval scale to calculate significant differences between comparison groups and to analyze whether these differences had statistically significant effects on the measured outcomes.

3) Multivariate Analysis

Multiple regression will be used to assess which services work best for which subjects who receive services. [Multiple regression is a statistical procedure for understanding the simultaneous effects of one or more characteristics (independent variables) on a dependent variable (early intervention).]

Survey

A survey will be sent to 1,000 parents of children who were enrolled in birth to three early intervention programs and are now enrolled in three to six programs. The survey will be similar to the one explained in the Pre-Post Study. The following is a review table of the types of questions that will appear on the survey.

CHILD/FAMILY OUTCOME AND SERVICE DESCRIPTION SAMPLE QUESTIONS FOR THOSE WHO RECEIVED B-3 SERVICES SERVICES

OUTCOME	SAMPLE QUESTION
Child Outcomes: 1) General Impact on Child	*Did early intervention make a difference in your child's life?* (Bailey et al., 1998)
Family Outcomes: 1) General Impact on Family	*Did early intervention assist you in building a strong support system?* *Did early intervention enable you to help your child grow, learn and develop?* (Bailey et al., 1998)
Services 1) Availability 2) Accessibility 3) Description of Services	*Who came up with the goals or "outcomes" for your child on his her service plan?* (National Early Intervention Longitudinal Study, Parent Interview Survey, 1998)

Questions regarding the family's transition experience would be a pertinent addition to this survey.

TIMELINE

The total time for the study is estimated at 2.5 years.

TIMELINE FOR RETROSPECTIVE CROSS-SECTIONAL STUDY

TASKS	5 mos	1 yr	1.5 yrs	2 yrs	2.5 yrs
Obtain cooperation from programs for 3-6 year old count Data Acquisition Form designed Submit proposal to HRRB* for 3-6 year old count Submit proposal to HRRB* approval for retrospective surveys Data Sharing/Confidentiality Agreements Three to six count packets mailed	X				
Process completed for 3-6 year old count Obtain HRRB* approval for retrospective surveys Process database information from DDD** and DOH*** Data entry Unduplicated count Match to services in B-3 counts Perform preliminary analyses Develop current address file for retrospective surveys		X			
Obtain passive consent from parents for retrospective surveys Send retrospective surveys Continue data analysis Follow-up of retrospective survey Telephone follow-up Identify comparison group Records review of survey recipients (with birth to three services) Report writing for profiles Data analysis of retrospective surveys Report writing of retrospective surveys			X		
Conduct standardized assessments and observations				X	
Write final report					X

* Human Research Review Board
** Division of Developmental Disabilities
*** Department of Health

DIRECT COST ELEMENTS

Cost estimates include only the direct costs of conducting the study. Indirect cost rates (to cover organizational overhead) vary widely depending on the type of organization, such as university, for-profit research center, or state agency. Depending on the specific indirect cost rate, indirect costs may represent 10 to 60 percent, or more, of the direct costs. With additional expenses for rent or lease for project space and indirect costs, total costs (direct plus indirect) could be **double** the estimated direct costs presented.

This study will incur the following direct cost elements:

* Participant Payment—subjects and service providers will be reimbursed for their time/effort in participation of the study
* Research Staff
* Supplies/Equipment
* Other (e.g. travel, postage)

TOTAL ESTIMATED DIRECT COST: $385,000

DISCUSSION

Identifying a comparison group relies on information obtained from parents whose children were not enrolled in birth to three services, but who are enrolled in three to six programs. Studies indicate a high level of response reliability for many questions related to infants with disabilities when asked at different points in time. Parents asked questions such as when they first realized that their child might be delayed and who first diagnosed their child, are likely to give the same response when their child is young as when their child is older (Carr, 1988; Palfrey, 1987).

Retrospective studies have demonstrated that receipt of services at an early age produces positive longitudinal effects (Moore et al., 1981).

ISSUES

General Issues

The general issues discussed in Child/Family Serves as Own Control—Large Scale Study should be review with regard to general social science research issues.

Strengths

The greatest strength of this study is that it provides an actual comparison group who did not receive services which would provide baseline outcome data against which to contrast target group (those that received birth to three services) data. If the comparison group could be matched on critical characteristics (see the section describing characteristics in Child/Family Serves as Own Control—Large Scale Longitudinal Study in this chapter),

conclusions could be made in regard to attributing changes in outcomes to early intervention.

Aside from outcome assessment, the study supplies additional information of interest such as. 1) identification of children and families who might be under-served, 2) perception of services from families who were enrolled in birth to three services, 3) perception of the transition experience from families who exited birth to three and entered three to six services, and 4) profiles of those families and children who received birth to three services and those that did not. Such information would be useful descriptive data to provide context within which to assess early intervention.

Another strength of this study is that is uses a variety of measurement techniques including structured and non-structured observation, surveys, and standardized tests. Such measures provide a balance of descriptive and numeric data which will allow a fuller interpretation of information collected and strengthen the merit of conclusions drawn.

Weaknesses

A major weakness of this study is accurately identifying the comparison group. The critical comparison group in this study is those children who were similar in disability and need to those who received intervention, and did not receive services. Defining this comparison group relies on information provided by the parents, and possibly the present severity of the child's condition and the etiology of the child's condition. The current severity of the child's delay *might* indicate whether or not birth to three services should have been provided. For instance, if a child has a severe motor delay at three that was not caused by a recent accident or occurrence, it is quite possible the motor delay was present before the age of three. The etiology of disabilities may assist in choosing the comparison group. Some disabilities such as Down Syndrome can be diagnosed at birth and children with the condition usually exhibit some sort of delay before three years of age. Studies have indicated that parent information with regard to when they noticed their child's delay and when and if their child was diagnosed is reliable, but there is no way to verify independently who would have qualified for services, even considering severity and etiology of condition at age three.

Once the comparison group is identified, comparability becomes a major issue. Group comparability is important to be able to attribute differences in scores to birth to three services. Since there are numerous independent variables that affect child and family development such as type and severity of delay, location of services, it may be difficult to match groups on a majority of these variables. There also may be group bias related to the reasons families were not enrolled such as they live in isolated areas, or they do not participate due to religious beliefs. Controlling for all of these factors would be problematic, especially since the effects of some different characteristics on child development are unknown. On a related issue, the subject number might not be large enough to control for comparability issues and achieve statistical significance. If these characteristics are not taken into account, attributing changes directly to early intervention may not be possible.

Another weakness of the study is the difficulty in verifying characteristics of services received. The parent survey will provide information in this regard, but the information may not be specific enough, or parents may not remember important details. The records review will help with verification. The process, however, relies on the accuracy and quality of the records as well as whether or not the records are available. If a full description of services cannot be obtained, attributing differences in assessment scores solely to receipt of birth to three services is problematic.

Problems may occur as a result of the cross-sectional design. Assessing children at one time may not provide the breadth of assessment information necessary to make strong conclusions. The researchers should be careful to point out that the assessment is a snapshot of outcome performance, and data should be interpreted within this framework. The data from this study could provide baseline data for future evaluations.

SUMMARY: STRENGTHS/WEAKNESSES/TIME/ESTIMATED DIRECT COST

Major Strengths:

- The study will provide a comparison group.
- The study will provide numerous sets of data of interest.

Major Weaknesses:

- There will be difficulty determining which children should have received early intervention services before the age of three.
- It is problematic to assign effects of early intervention strictly to birth to three programs.
- Group comparability is problematic.

ESTIMATED DIRECT COST:	**$385,000**
ESTIMATED COMPLETION TIME:	**2.5 years**

KEY INFORMANT STUDY

DESCRIPTION

The study examines perceptions of key informants across Washington State regarding child and family outcomes, and provision, quality, and needs of early intervention services for infants/toddlers and families with delaying or disabling conditions. Two approaches will be discussed: the **three-tiered approach**, which uses interviews and focus groups to select outcomes before conducting a written survey, and the **survey-only approach** which begins with pre-established outcomes and uses survey questions that are already developed.

THREE-TIERED APPROACH

Outcomes

The aim of the open-ended interviews with a small sample of parents and service providers is to suggest child and family outcomes. The focus groups will provide feedback regarding the outcomes derived. The qualitative data collected during these processes will provide a rich context within which to interpret survey results.

Methods

(1) Qualitative interviews with parents and service providers
(2) Focus groups with parents and service providers
(3) Written survey of parents and service providers

SURVEY-ONLY APPROACH

Child Outcomes: (1) Child Development (2) Quality of Life
(3) Child Interaction/Behavior

Family Outcomes: (1) Support (2) Quality of Life
(3) Knowledge (4) Empowerment

Services: (1) Description of Services

METHODS

(1) County Interagency Coordinating Council (CICC) Survey
(2) Survey of Service Providers
(3) Survey of Parents
(4) County Interagency Coordinating Council (CICC) Focus Groups

Major Strengths:

Both Approaches

- The study will access the knowledge and experience of those directly participating in early intervention services and is multidimensional.
- The study provides good description of services across various geographic areas.
- The study provides both qualitative and quantitative data.

Three-Tiered Approach

- Directly involves parents and service providers in development of the assessment tool.
- Provides rich qualitative data within which to interpret survey results.

Major Weaknesses:

Both Approaches

- There is no direct assessment of outcomes or service delivery and characteristics.

ESTIMATED DIRECT COST:	
Three-tiered Approach	**$470,000**
Survey-only Approach	**$325,000**

ESTIMATED COMPLETION TIME:	
Three-tiered Approach	**2.5 years**
Survey-only Approach	**1.5 years**

KEY INFORMANT STUDY

SUMMARY

This study is a qualitative exploration of the status of early intervention services in the state of Washington and its impact on children, birth to three, with disabling or delaying conditions and their families. The study examines perceptions of key informants across the state regarding child and family outcomes; and provision, quality, and needs of early intervention services for children and families with delaying or disabling conditions in their communities.

INTRODUCTION

This study draws upon the perceptions and attitudes of those participants who are in key positions to observe and appraise early intervention services in the state of Washington in order to assess the impact of those services on children with delaying or disabling conditions and their families.

Three-Tiered Approach

The three-tiered approach proceeds from the idea that child and family outcomes should be selected directly from the input of early intervention participants, particularly parents and service providers. This approach involves three steps: 1) open-ended interviews with parents and service providers, 2) focus groups with parents and service providers, and 3) a written survey of parents and service providers. The aims of the open-ended interview with a small sample of parents and service providers are to collect qualitative data to provide a rich context within which to interpret survey results, and to derive suggestions of possible child and family outcomes. The purpose of the focus groups is to gather feedback regarding the outcomes derived, and to gather additional contextual qualitative data. From the results of the interviews and focus groups, outcomes will be selected and survey questions developed.

Survey-Only Approach

The survey-only approach uses child and family outcomes determined by previous studies, and gathers data through a written survey of key informants and small focus groups. Such informants include service providers, parents, and community groups. The community groups chosen for the survey are the County Interagency Coordinating Councils (CICCs). CICC members represent health departments, medical providers, school districts, parents, service providers, and other public and private agencies. The CICCs plan and coordinate services at the community levels and aid communities in achieving Part H goals. Since CICC members include those vital to the functioning of early intervention programs, they are a rich source of key informants and provide a fruitful focus point for this study.

Three surveys will be developed for use in the study: 1) the family survey, 2) the service provider survey, and 3) the County Interagency Coordinating Council (CICC) survey. The family and provider survey will contain virtually the same questions, only asked from

the relevant perspective. The CICC survey will focus more on provision of services and will inquire about family and child outcomes only in a general way (see the subsequent section, County Interagency Coordinating Council Survey, Survey-Only Approach, Child and Family Outcomes). The focus groups will occur at CICC meetings to provide qualitative contextual data.

METHODS—THREE-TIERED APPROACH

Eligibility and Recruitment

Qualitative Interviews

It is suggested that open-ended qualitative interviews should be conducted with twenty service providers and twenty parents (n=40 total). Selection of these participants should be carefully thought out. Various geographic locations should be represented, parents and service providers of children with various conditions should be included, as well as those with different opinions regarding early intervention services. If parents of children who are eight to ten years old can be located, several should be interviewed to provide a longitudinal perspective. The 1993 Research and Data Analysis child count database can be used to identify these parents. Informal conversations with service providers and parents could aid in selection of interview participants.

Focus Groups

At least nine locations strategically selected across Washington State should be established for focus group locations. At the nine locations, one focus group should be held for parents and one for service providers for a total of eighteen focus groups. Locations should be representative of various regions in Washington State.

Survey

Those eligible for the study are families who are included in the early intervention child enrollment counts. The sample size will include 1,000 families and their service providers (n=2,000 total) and will be selected randomly to receive a mailed survey. The service providers of these families will receive a survey for *each* family under their care. A percentage of the number of families (n=1,000) should include those whose children are older to provide a longitudinal perspective. (The 1993 Research and Data Analysis child count database can be used to identify these parents.)

Interviews

After participants are selected, open-ended interviews will be conducted. The aims of the interview are to identify some possible outcomes and to gather contextual descriptive data. While the trained interviewer should be sure to gather feedback regarding outcomes, the other content of interview can be quite unstructured. Open-ended interviews can be used as an exploratory tool to draw out points not previously considered by the researcher. The information will then be coded and prevalent themes identified.

Focus Groups

Similarly, the focus groups will be unstructured. The aim of these groups is to provide feedback on outcomes which arose from the interviews and provide another source of contextual descriptive data. Discussion will last approximately three hours, so it is feasible to do both focus groups (parents and service providers) in one day.

Survey

From the input of parents and service providers, outcomes will be selected and pertinent survey questions developed. The survey can either draw from other established surveys if questions are appropriate for the outcomes, or create a new survey. If the latter is chosen, a small pilot study of the survey should be conducted in order to refine the questions.

Child and Family Outcomes

Child and family outcomes will be derived from the qualitative interviews and focus groups.

Description of Services

In order to gain some idea of what kind of services children and families are receiving, a description of services must be included as part of the survey. Questions should revolve around identified relevant program characteristics (see Appendix B and the following section Description of Services for example questions).

METHODS—SURVEY-ONLY APPROACH

Eligibility Criteria and Sample Size

Those eligible for the study are families who are included in the most recent early intervention child enrollment count. The sample size will include 1,000 families and will be selected randomly to receive a mailed survey. The service providers of these families will receive a survey for *each* family. All County Interagency Coordinating Councils (35) will be contacted.

Sample numbers therefore include the following: 1,000 family surveys and 1,000 service provider surveys. The number of County Interagency Coordinating Council (CICC) participants will depend on meeting attendance.

Recruitment of Families and Service Providers

Families will be randomly selected from the child count conducted by Research and Data Analysis of the Department of Social and Health Services. Once these families are identified, their service providers will be contacted. The service providers will then contact the families to obtain consent for researchers to contact them (via passive consent forms). Providers will then furnish addresses of the families that agree to participate.

Researchers will send families the family survey, and providers will be sent the service provider survey. All those who complete a survey will be reimbursed for their time, and service providers will be paid an hourly rate for their time involved in recruitment.

County Interagency Coordinating Council (CICC) Written Survey and Focus Groups

The written survey will be presented to CICC meetings with a brief explanation of its purpose and aims. Researchers will request approximately four hours of meeting time to conduct the study survey and focus groups. The first 45 minutes of the meeting will involve completion of the written survey. After a short break, focus groups will take place over a three hour period. The remainder of the meeting will be spent gathering suggestions and information regarding possible other community members to whom the written survey will be mailed.

Possible focus group questions could include the following:

1) In the past five years, what were major influences that supported the implementation of Part H in your county?

2) What are positive outcomes of early intervention for children? Families? Your community?

3) What are the major accomplishments achieved by early intervention services in your area during the past five years?

4) In the past five years, what were major problems that interfered with the implementation of Part H in your county? What resolutions to these problems have been attempted? Were they effective?

5) What problems still remain? How large are they?

6) In the past five years, what barriers to services were there? What solutions to these barriers have been attempted? Were they effective?

7) What objectives would you set with regard to early intervention in the next five years?

Child Outcomes and Measures

The child outcomes include the domains: 1) Child Development, 2) Quality of Life, and 3) Child Behavior/Interaction. These outcomes were selected because of their general applicability to many families, and because feedback on these outcomes is readily attainable in the survey format. Since child outcomes will be evaluated from the perspective of the parents and service providers, questions should be worded to reflect these different viewpoints. Questions will be based on Likert Scale ratings for data

analysis. The following tables present example questions in each of the child outcome domains.

CHILD OUTCOMES AND SAMPLE SURVEY QUESTIONS FOR THE KEY INFORMANT STUDY

CHILD OUTCOME	SAMPLE QUESTIONS	
	Family	**Service Provider**
Child Development	*Has early intervention helped in improving your child's development?* (Scale: Very much⇒not at all)	*Has early intervention helped in improving "John's" development?* (Scale: Very much⇒not at all)
Quality of Life	*Does your child show interest in others?'* (Scale: Very much ⇒not at all)	*Does "John" show interest in others?* (Scale: Very much ⇒not at all)
Child Behavior/Interaction	*Would you say your child smiles in response to something he she likes?** (Scale: Very much⇒not at all)	*Would you say "John" smiles in response to something he she likes?* (Scale: Very much⇒not at all)

* NEILS Parent Interview Survey, 1998

Family Outcomes and Measures

Family outcome domains will include the following: 1) Social Support, 2) Quality of Life, 3) Knowledge, and 4) Empowerment. The following table contains suggested questions.

FAMILY OUTCOMES AND SAMPLE SURVEY QUESTIONS FOR THE KEY INFORMANT STUDY

FAMILY OUTCOME	SAMPLE QUESTIONS	
	Family	**Service Provider**
Support	*How has the help and information [from early intervention services] affected your family? Is your family ...?* (Scale: Much better off ⇒ Worse off)	*How has the help and information [from early intervention services] affected "the Smiths"? Are they ...?* (Scale: Much better off ⇒ Worse off)
Quality of Life	*We, as a family, have been able to participate in community activities.*+ (Scale: Strongly agree⇒strongly disagree)	*"The Smiths" have been able to participate in the community activities.* (Scale: Strongly agree⇒strongly disagree)
Knowledge	*Did early intervention enable you to help your child grow, learn, and develop?*++ (Scale: Very much⇒not at all)	*Did early intervention enable "the Smiths" to help their child grow, learn, and develop?* (Scale: Very much⇒not at all)
Empowerment	*I have regular opportunities to consider a variety of options and make choices.*• (Scale: Strongly agree⇒strongly disagree)	*"The Smiths" have regular opportunities to consider a variety of options and make choices.* (Scale: Strongly agree⇒strongly disagree)

+ NEILS Parent Interview Survey, 1998
• Early Childhood Connections Family Survey: The Statewide Report, The Colorado Foundation for Families and Children, 1997
++ Bailey et al., 1998

County Interagency Coordinating Council (CICC) Survey—Child and Family Outcomes

Child and family outcomes can be addressed in a general way in the CICC survey. For example:

Overall, how would you rate the impact of early intervention services:

a) On your community?
(1=large impact; 2=some impact; 3=a little impact; 4=no impact)

b) On families?
(1=large impact; 2=some impact; 3=a little impact; 4=no impact)

c) On children?
(1=large impact; 2=some impact; 3=a little impact; 4=no impact)

Description of Services

County Interagency Coordinating Council (CICC) Survey

The family, service provider, and CICC survey will all contain questions regarding the description of services. The family and service provider questions regarding services will focus on a specific child and family. The CICC survey will concentrate on description of all services in the community. Questions should address areas such as: 1) availability of services, 2) accessibility of services, 3) demand for services, and 4) utilization of services. Other domains could include questions regarding: 1) the degree of coordination among programs, 2) the comprehensiveness of services, 3) the degree to which services are family centered, and 4) how well services are supported by the community.

An example of a CICC survey question follows:

EXAMPLE CICC SERVICE DESCRIPTION QUESTION

For each of the following services/programs indicate:

- whether it is available to your county (yes/no)
- to what extent it is accessible
- to what extent there are currently sufficient providers to meet the demands for services
- to what extent do enrolled early intervention children appropriately utilize the service

Services	Available? yes/no	Accessible? not easy 1 2 3 4 5 very easy	Sufficient providers? not at all 1 2 3 4 5 very much	Families appropriately utilize the service? not at all 1 2 3 4 5 very much
Assistive technology devices and services				
Early identification, screening, and assessment services				
Family training, counseling, and home visits				
Health services				
Nutrition services				
Occupational therapy				
Physical therapy				
et cetera				

Families and Service Providers

While service description domains will be similar to the County Interagency Coordinating Council (CICC) survey, families and service providers will be asked to describe services specific to the child and family.

SERVICE DESCRIPTION SAMPLE SURVEY QUESTIONS

SERVICE DESCRIPTION	SAMPLE QUESTIONS	
	Family	**Service Provider**
Awareness of Individualized Family Service Plans	*Are you aware of a written plan that describes goals(outcomes) for your child and the services they receive?* (Scale: Yes/No/Don't Know)	*Are "the Smiths" aware of a written plan that describes goals (outcomes) for your child and the services they receive?* (Scale: Yes/No/Don't Know)
Degree services are family centered	*Who came up with the goals or "outcomes" for your child on his her service plan?* (Scale: Family/Providers/Both)	*Who came up with the goals or "outcomes" for "John" on his her service plan?* (Scale: Family/Providers/Both)

+ NEILS Parent Interview Survey, 1998

TIMELINE

Three-Tiered Approach

The total time for the study is estimated at 2.5 years.

TIMELINE FOR THE KEY INFORMANT STUDY
THREE-TIERED APPROACH

TASKS	5 months	1 year	1.5 years	2 years	2.5 years
Organize staff Submit proposal to HRRB* for interviews, focus groups, and surveys Obtain cooperation from programs Informally contact service providers and communities regarding possible interview participants and focus group sites Conduct interviews	X				
Analyze interview information Conduct focus groups		X			
Analyze qualitative data Design survey Pre-test survey Develop current address file			X		
Obtain passive consent from parents for survey Send survey Telephone follow-up				X	
Data analysis of survey Report writing of survey					X

* Human Research Review Board

Survey-Only Approach

The total time for the study is estimated at 1.5 years.

TIMELINE FOR THE KEY INFORMANT STUDY
SURVEY-ONLY APPROACH

TASKS	5 months	1 year	1.5 years
Design survey with input from key informants Submit proposal to HRRB* for study Obtain cooperation from programs Submit proposal to HRRB* for survey Pre-test survey Develop current address file	X		
Obtain passive consent from parents for survey Send survey CICC** meeting CICC** follow-up Telephone follow-up		X	
Data analysis of survey Report writing of survey			X

* Human Research Review Board
** County Interagency Coordinating Council

DIRECT COST ELEMENTS

Three-Tiered Approach and Survey-Only Approach

Cost estimates include only the direct costs of conducting the study. Indirect cost rates (to cover organizational overhead) vary widely depending on the type of organization, such as university, for-profit research center, or state agency. Depending on the specific indirect cost rate, indirect costs may represent 10 to 60 percent, or more, of the direct costs. With additional expenses for rent or lease for project space and indirect costs, total costs (direct plus indirect) could be **double** the estimated direct costs presented.

This study will incur the following direct cost elements:

* Participant Payment—subjects and service providers will be reimbursed for their time/effort in participation of the study
* Research Staff
* Supplies/Equipment
* Other (e.g. travel, postage)

TOTAL ESTIMATED DIRECT COST:

Three-tiered Approach	**$470,000**
Survey-only Approach	**$325,000**

DISCUSSION

Given the methodological difficulties associated with scientific evaluation of the impact of early intervention services (Casto and White, 1993; Eayrs and Jones, 1992; Mott et al., 1986; Casto and Mastropieri, 1986), many state and federal governments have turned to key informant surveys to gain a greater understanding of the need and impact of services in a given area, and to ascertain the perceived impact of early intervention on children with disabling or delaying conditions and their families (see Chapters 3 and 4). By contrasting the perceptions of service providers and service receivers, a multidimensional assessment of early intervention can occur.

Three-Tiered Approach

The major advantage of the three-tiered approach is derived from the inclusive participation of service providers and parents in developing research tools. Green and McAllister (1998) explain why research benefits from the participatory evaluation method:

- Such a method provides a format for evaluators, practitioners, and family members to share their thoughts about how and why a program works.
- The evaluation tool more accurately reflects the actual program process and intended outcomes.
- The method encourages a systematic, commonly understood method for prioritizing evaluation activities.
- The method provides a framework for sharing information with programs and parents.

Direct involvement of service providers and parents at the ground level of planning allows them to become part of the evaluation project rather than be subjects outside of the project. Cooperation among researchers, program personnel, and parents provide the framework for mutually beneficial activities. When participants actually become interested in the study and its results, the conduct of the study is facilitated.

Survey-Only Approach

The survey-only approach takes advantage of previous child and family outcome research and survey development. Many surveys have been developed to gather qualitative information regarding child and family outcomes. Given the cost and methodological difficulties of direct assessment studies, surveys often have been the method of choice for states seeking to evaluate their programs (see Chapter 4, Development of Child and Family Outcomes at the State Level). While the survey-only approach does provide qualitative contextual data through the use of County Interagency Coordinating Council (CICC) focus groups, this qualitative data is not used to develop the assessment tool.

ISSUES

Strengths—Both Approaches

The greatest strength of this study is that it provides information on child and family outcomes and service provisions from a multidimensional viewpoint. In both approaches, those directly involved with services are the source of the data. Comparing the perceptions of service providers and parents will provide insightful qualitative and quantitative data to gain a multidimensional view on the intent and outcome of services. Such information will not only be useful for evaluation, but would be valuable for programs in planning future program goals and objectives.

Given that 2,000 people will participate in the survey, the methodology allows a broad array of parents and services providers from different geographical locations across Washington State to participate in the project. The large number and variety of participants strengthens the generalizability of results which is important to attaining information that can be applied statewide.

Both approaches allow descriptive data to be collected to provide a context within which to interpret more quantitative data. Without such descriptive data, survey results will have no interpretive framework, which could weaken the strength of conclusions.

Three-Tiered Approach

The greatest asset of this approach is that it directly involves parents and service providers in development of the assessment tool. Such an approach reflects recent trends in the field of evaluation. As was discussed in Chapter 3 (Development Of Family And Child Outcome Measures At The Federal Level), the Early Childhood Research Institute national research team recognized that "the future use of the general growth outcomes would hinge greatly on acceptance by families, teachers, administrators, and other individuals involved in early childhood education" (Early Childhood Research Institute on Measuring Growth and Development, Draft Report, 1998) and directly incorporated key informants into the development of their outcomes. By involving service providers and parents at the ground level of the research project, motivation to participate fully in the project will increase (Presentation, Dr. Susan Janko, 2/6/98).

Another strength of this approach is that it allows flexibility in the selection of outcomes. By first conducting qualitative interviews and focus groups with service providers and parents, outcomes previously not considered might emerge. The open process allows a fuller, less pre-defined discussion of which outcomes may be beneficial to include.

Survey-Only Approach

The main strength of this study is that it draws on previously developed material which reduces time and cost commitments. From a feasibility standpoint, the study will provide valuable information in a quick time frame for a relatively low cost.

Including the County Interagency Coordinating Council (CICC) focus groups provides a third perspective and allows the collection of qualitative contextual data. Thus the study draws from three perspectives, service providers, parents and CCIC members.

Weaknesses—Both Approaches

The greatest weakness of the Key Informant Study is that child and family outcomes are not directly assessed. While child and family outcomes are a part of this study, conclusions regarding the impact of early intervention services on these outcomes are problematic. In order to assign changes in child and family outcomes as expressed by parents and service providers strictly to early intervention services, other influencing factors, such as child and family characteristics and a detailed description of services received would have to be taken into account. While some of this information will be gathered in the survey, such as description of services, the study does not provide a method to verify this information. Conclusions regarding the impact of early intervention are based solely on information provided in the survey, which is restrictive in the sense that it is not balanced by other types of data such as that produced from observation.

SUMMARY: STRENGTHS/WEAKNESSES/TIME/ESTIMATED DIRECT COST

Major Strengths:

Both Approaches

- The study will access the knowledge and experience of those directly participating in early intervention services and is multidimensional.
- The study provides good description of services across various geographic areas.
- The study provides both qualitative and quantitative data.

Three-Tiered Approach

- Directly involves parents and service providers in development of the assessment tool.
- Provides rich qualitative data within which to interpret survey results.

Major Weaknesses:

Both Approaches

- There is no direct assessment of outcomes or service delivery and characteristics.

ESTIMATED DIRECT COST:	
Three-tiered Approach	**$470,000**
Survey-only Approach	**$325,000**
ESTIMATED COMPLETION TIME:	
Three-tiered Approach	**2.5 years**
Survey-only Approach	**1.5 years**

CHAPTER 8

DISCUSSION AND RECOMMENDATIONS

The study designs in this report represent a variety of ways to assess the impact of early intervention services on infants and toddlers, birth to three, with disabling or delaying conditions and their families in Washington State. As is evidenced by the intricate nature of some of the studies, early intervention is "a complex and multidimensional experience that defies simple description" (Shonkoff et al., 1992), which makes assessing its impact even more complex.

The following three factors need to be taken into consideration when choosing one of these study designs: 1) the specific aim of the study, 2) the costs within which the aim is to be achieved, and 3) the duration of time needed to complete the study. It should be noted that all of the studies have certain merits and drawbacks. As a result, there is no perfect study, and the choice is not an easy one. A summary of the estimated costs and duration of time for each study is presented in the table below.

SUMMARY OF STUDY DESIGNS, COST, AND TIME SPAN

STUDY	TIME SPAN	ESTIMATED DIRECT COSTS
Child/Family Serves as Own Control—Large Scale Longitudinal Study	10 years	$3.2-3.6 million
Child/Family Serves as Own Control—Small Scale Longitudinal Study	3.5 years	$1.4 million
Comparison Group Longitudinal Study	12 years	$4 million
Pre-Post Study	1.5 years	$385,000
Retrospective Cross-sectional Study	2.5 years	$715,000
Key Informant Study Three-tiered Approach Survey-only Approach	 2.5 years 1.5 years	 $470,000 $325,000

RECOMMENDATIONS

Recommendation One

Research and Data Analysis and the majority of the Advisory Group chose the Child/Family Serves as Own Control—Small Scale Longitudinal Study as their first choice to address the question: *what is the impact of early intervention services on children, birth to three, with disabling or delaying conditions and their families in Washington State?* The following points were made:

- This study links child outcomes to program characteristics thereby allowing one to attribute change to early intervention.
- Given the difficulty in locating a proper comparison group, children serving as their own control is the best option.
- In order for the impact of early intervention to be assessed accurately, a large enough study sample must be recruited to control for background variables which affect child and family development.
- The smaller scale study will reduce estimated costs and time, yet still attain a high subject number and control for independent variables.

Several members of the Advisory Group felt a small, but intensive, ethnographic study (six months-one year) of a small sample of children and families should be conducted prior to this study in order to provide rich, holistic portraits of what early intervention means for these children and families. A survey aimed at evaluating the generalization of results emerging from the ethnographic study could be conducted in order to discern which child and family outcomes to use for the recommended study.

Recommendation Two

If the first choice of Child/Family Serves as Own Control—Small Scale Longitudinal Study proves to be too expensive and the time for completion too long, Research and Data Analysis and the Advisory Group recommend two different options.

Research and Data Analysis recommends the Retrospective Cross-sectional Study as a less expensive and shorter timeline option. They pointed out the following strengths:

- This study design will provide a comparison group of children and families who did not receive early intervention services.
- This study allows analysis of other issues in early intervention including transitioning of children from birth to three early intervention programs into programs for three to six year olds and identification of under-served or under-identified children.

The three-tiered approach of the Key Informant Study was chosen by the majority of the Advisory Group as a second choice if there was not enough funding available to do the Child/Family Serves as Own Control—Small Scale Longitudinal Study or a full ethnographic study. The following points were made:

- This study's participatory nature in accessing knowledge and experience of families and service providers will result in identifying meaningful child and family outcomes for Washington State.

- The study design includes a combination of qualitative and quantitative data.

DISCUSSION

Child/Family Serves as Own Control—Small Scale Longitudinal Study

Both Research and Data Analysis and the majority of the Advisory Group recommended the Child/Family Serves as Own Control—Small Scale Longitudinal Study as the first choice of the six study designs presented in this report. This study offers a triangulation of measurement where multiple methods, both quantitative and qualitative, are employed. Scores of standardized and non-standardized tests are complemented by more open-ended methods such as observation, interviews, and case studies. Quantitative and qualitative results will provide a comprehensive picture of the impact of early intervention. Observation of the early intervention environment/program will allow a measure of program characteristics, thereby allowing a link between child outcomes and early intervention services.

Two general strategies might be pursued to obtain funding for such a study: applying for a federal grant or obtaining state funding. If federal grant funding is pursued, it might require one to two years (or more) to obtain funding, and additional investment in developing and submitting a formal proposal would be required. If state funds were made available, a request for proposals (RFP) could be developed. The RFP process would also require time and money, and actual budget proposals from bidders might exceed the budget estimates in this report, perhaps by a considerable amount.

It is unlikely that such a study could be initiated before the year 2000.

Retrospective Cross-Sectional Study

The Retrospective Cross-sectional Study provides a comparison group of children that did not receive birth to three early intervention services. While isolating an appropriate comparison group is problematic, the study allows examination of a number of pertinent factors such as 1) identification of children and families who might be under-served, 2) description of services from families who were enrolled in birth to three services, 3) perception of the transition experience from families who exited birth to three and entered three to six services, and 4) profiles of those families and children who received birth to three services and those that did not. This study is relatively inexpensive and can be completed in a short amount of time.

SUMMARY OF STRENGTHS AND WEAKNESSES

STUDY	*Child Family Serves as Own Control—Large Scale Longitudinal Study*	*Child Family Serves as Own Control—Small Scale Longitudinal Study*	*Comparison Group Longitudinal Study*	*Pre-Post Study*	*Retrospective Cross-sectional Study*	*Key Informant Study*
STRENGTHS	Determines which program components work for which children/ families Controls for major variables influencing child and family outcomes	Determines which program components work for which children/ families Controls for major variables influencing child and family outcomes Provides triangulation of measurement	Provides an actual comparison group Allows comprehensive longitudinal assessment	Provides descriptive profile data Allows comparison of pre- and post-Part H full implementation years, 1993 and 1997	Provides a comparison group Provides numerous sets of data of interest	<u>Both Approaches</u> Uses knowledge of key informants Is multidimensional Provides good description of services across various geographic areas <u>Three-tiered Approach</u> Directly involves parents and service providers in development of the assessment tool
WEAKNESSES	Conclusions rely heavily on change score models Instrument sensitivity, validity Estimated cost and time of completion	Conclusions rely heavily on residual change score and change score models	Difficulty obtaining sufficient numbers of non-enrolled children and families who are willing to cooperate Group comparability	No precise pre/post demarcation Outcomes not directly assessed Problems assigning effects of early intervention strictly to birth to three programs	Difficulty determining which children should have received services before age three Problems assigning effects of early intervention strictly to birth to three programs Group comparability	<u>Both Approaches</u> No direct assessment of outcomes or service delivery and characteristics

Members of the Advisory Group felt that while the Retrospective Cross-sectional Study has a comparison group, there would be a problem with group comparability including potentially different child and family characteristics of those who received early intervention and those who did not. With the knowledge of the interaction between child characteristics, family characteristics, program components and child outcomes, controlling for the differences in groups may require a much larger subject number. It would be important to determine the reason families are not coming into the early intervention system which may include religious reasons, health reasons, education, referral patterns, availability and access of services in different geographic areas, or type of private insurance. There was also a concern about not being able to determine specific program characteristics for those who received early intervention services due to the retrospective nature of this design. Records of an individual's services may not be available nor would observation of the child in the early intervention environment be possible.

Longitudinal Comparison Group Study

While the Longitudinal Comparison Group Study would theoretically provide the most useful comparison group, it is not known whether a large enough subject sample could be recruited or would be willing to participate in a 12 year study.

Pre-Post Study

The Pre-Post Study provides a relatively inexpensive way to compare impressions of services before (1993) and after (1997) full implementation of Part H in October 1994. It also provides profile information on these two groups which would be useful. However, implementation of the Part H program in Washington State occurred in stages. For example, Family Resources Coordinators were phased in, beginning with the addition of Interim Family Resources Coordinators in 1991. Similarly, regional differences in the degree of implementation in specific years may exist. Since the components of the Part H program were phased in over varying time periods, it appears that a precise demarcation between pre- and post-Part H full implementation does not exist. This study design does not yield direct child assessment or service provision information.

Key Informant Study

Both the three-tiered and survey-only approach of the Key Informant Study offer simple, relatively inexpensive study design options and can be completed in a short time span. Both approaches include the combination of qualitative and quantitative data, access the knowledge and experience of service providers and families, and provide a description of services across geographic areas in the state. Although these methods do not directly measure child outcomes with tests or observation, many states are choosing similar approaches, due to the costs and difficulties of measuring outcomes.

Three-Tiered Approach

The major strength of the three-tiered approach is its state-of-the-art participatory approach to evaluation—the direct involvement of families and service providers in the development of the outcomes and assessment tool (Green and McAllister, 1998). The Advisory Group pointed out that although this study design would not yield direct child assessment data, it would result in the identification of meaningful outcomes through the interviews and focus groups. These outcomes could then be incorporated into relevant survey questions to determine their generalizability in Washington State.

Survey-only Approach

The survey-only option of the Key Informant Study would be the least expensive of the two approaches, as it would incorporate previously developed surveys. However, it lacks the extent of qualitative data available in the three-tiered approach. This approach, like the three-tiered option, has no direct assessment of child outcomes or service provision.

Future Directions

A number of evaluations and assessment activities are currently ongoing which will enhance the pool of knowledge regarding evaluation. Local, state, and national activities regarding the evaluation of early intervention services are likely to produce materials that will be beneficial to Washington State's assessment efforts. Some of these projects that should be carefully tracked as their results become available include those listed in the table on the following page.

PROJECTS TO MONITOR

NAME OF STUDY	TYPE OF INFORMATION	ESTIMATED DATE AVAILABLE
The Early Child Care Study of Children with Special Needs Phase 1	Child Characteristics Family Characteristics Child Care Characteristics Early Intervention Characteristics Child and Dyadic Outcomes	Fall 1998
The Early Child Care Study of Children with Special Needs Phase 2	Child Outcomes Transition Outcomes Inclusion Outcomes School-Age Outcomes	Phase 2 Grant Funding Pending
OSPI Longitudinal Database	Information pending	2000
Neurodevelopmental Centers of Washington Outcome Measurement Project	Recommendation concerning use of WeeFIM as an outcome measurement tool for all 14 neurodevelopmental centers	November 1998
Snohomish County Birth to Three Review Project	Review of birth of three services in Snohomish County Recommendations for future directions	July 1998
National Early Intervention Longitudinal Study (NEILS)	Child Outcomes Family Outcomes Survey Tools	2003 is the anticipated completion date. The listed materials will be available before then. Surveys and outcomes are already in advanced draft form.
Early Childhood Research Institute on Measuring Growth and Development (ECRI-MGD)	Child Outcomes Family Outcomes Instruments Tracking method from birth to eight	2001 Child Outcomes-July 1998

Review of these studies as they are completed would contribute to Washington State's development of assessment plans in that selected outcomes and instruments would have already been field tested. Since appropriate outcome measures and instruments may be well defined in the short term by some of these studies, it may be efficient for Washington to take advantage of the results of these projects that were started some time ago. Local efforts could reveal information regarding which assessment methods work well *in Washington*. Such information would save time and resources when planning for Washington State's evaluation study.

An opportunity to analyze existing data collected for a different purpose was also discussed. The Early Child Care Study of Children With Special Needs Part 1 (Booth and Kelly, principal investigators; see Chapter 5) was designed to evaluate the effects of child care; receipt of early intervention services was included in the data collected for this study. The data could be analyzed differently than originally planned to explore the effects of early intervention specifically. This approach could provide an excellent pilot study before proceeding with a larger study. As the focus of this study was child care, there were no observations in the early intervention environment and therefore no measure of program characteristics to link to child outcomes. Although the sample of children in the Early Child Care Study of Children With Special Needs was limited to the Puget Sound area and might not be representative of children across Washington State, analysis of these data could provide better estimates of the magnitude of the effects of early intervention and evaluate the usefulness of, and variability in, the outcome measures collected. This strategy could not be pursued without the cooperation of the principal investigators and perhaps the permission of the original funding agency.

Summary

With regard to which outcome study most effectively addresses the question—*what is the impact of early intervention services on children, birth to three, with disabling or delaying conditions and their families in Washington State*—Research and Data Analysis (RDA) and the Advisory Group recommend the Child/Family Serves as Own Control—Small Scale Study. Given that this study is quite costly, and will take three to four years to complete, RDA and the Advisory Group each made secondary recommendations which are less expensive and require less completion time. RDA recommends the Retrospective Cross-sectional Study, and the Advisory Group recommends the Key Informant Study—Three-tiered Approach.

These recommendations are outcome study recommendations. During the process used to complete this report, however, the need for a more comprehensive approach to evaluation of early intervention in Washington became evident. Based on all the information gathered during this process, and given the stated difficulties of conducting good outcome studies, Research and Data Analysis felt it necessary to make a broader recommendation. This alternative approach to evaluating early intervention is explained in the next chapter (Chapter 9).

CHAPTER 9

FUTURE DIRECTIONS
RECOMMENDATIONS FOR WASHINGTON STATE

INTRODUCTION

The focus of this study was the development of study designs and outcome measures to address the impact of early intervention on infants and toddlers with disabling or delaying conditions and their families in Washington State. To accomplish this task, child and family outcomes were identified, and studies were designed to assess program impact on these outcomes. In Chapter 8, these proposed studies were discussed and several recommendations from the Advisory Group and Research and Data Analysis regarding outcome studies were made. During the course of this report, however, important information has come to the forefront that extends beyond the narrow scope of the project—outcome evaluation, but is critical to accomplishing the aims of the project—early intervention evaluation.

Based on an extensive review of the literature, discussions with the Advisory Group, site visits, and review of federal, state and local efforts with regard to child and family outcome assessment and its difficulties, it became evident that a more comprehensive approach to early intervention evaluation in Washington was necessary. This chapter discusses such an option.

Research and Data Analysis, therefore, makes the following recommendation:

GENERAL RECOMMENDATION

- To design an **integrated** research plan that logically and methodically addresses four questions:

    1) who are the children and families receiving services?
    2) what are their needs?
    3) how are programs addressing their needs?
    4) what child and family outcomes occur as a result of services?

To address these questions, Research and Data Analysis recommends the following steps:

Step One: Who Are the Children and Families Receiving Services? • Use enhanced profiles in annual child count to describe the children and families who are receiving early intervention in Washington State.
Step Two: What Are Their Needs? • Conduct a needs assessment of children and families who are receiving early intervention services in Washington State using focus groups, interviews, and surveys.
Step Three: How Are Services Addressing The Needs of Children and Families? • Conduct a review of program services provided to children with disabling or delaying conditions and their families in Washington State using monthly service reports and program observation.
Step Four: What Child and Family Outcomes Occur as A Result of Service Provision? • Conduct an outcome study which identifies positive child and family outcomes occurring as a result of early intervention services in Washington State.

DISCUSSION

What We Know

A review of early intervention research has shown that the question of whether early intervention has a positive impact on children with disabling or delaying conditions and their families has been answered on several levels. Brain research has shown that early stimulation in infants is necessary for development of neural synapses which form patterns of behavior and learning style (Huttenlocher, 1990). First generation research has produced results which have indicated the positive impact of early intervention programs (see Chapter 7). Second generation research has not only shown that early intervention is effective, but has been able to draw more specific conclusions such as highly structured programs are more effective than less structured programs for children with autism (Dawson and Osterling, 1997; and see Chapter 7). Federal policy has acknowledged the importance and success of early intervention through both Part H (Part C) of Individuals with Disabilities Education Act (IDEA) and bills currently submitted that require early intervention to be fully federally funded (House Resolution 131, 105th Congress). In short, multidisciplinary evidence that indicates early intervention has a positive impact is abundant, and numerous sound research studies have shown which type of intervention is most effective for which type of children and families (see Chapter 7).

Research in the area of early intervention is very active. Hundreds of research projects (some taking place in Washington) are exploring a variety of topics related to early intervention. Such studies examine which curricula are more effective for which types of children, better techniques for measuring change in development for children with

disabling or delaying conditions, topics in the process of child development itself, identification of critical factors in child development (characteristics) and their relationships, as well as identification of the etiology of certain conditions (http://www.cec.sped.org/osep/8earlych.htm, 5/22/98; http://www.nectas.unc.edu/eepcd/demos.htm#abstract, 5/22/98).

Since it is generally accepted by many parents, legislators, researchers, child development experts, and stakeholders that early intervention has a positive impact on children with disabling or delaying conditions and their families, it would appear redundant to research this question in Washington when it has already been answered so thoroughly. And, given the amount and variety of current research which explores different factors of how early intervention works with specific families and children, it would seem unnecessary for Washington State to conduct this sort of research investigation as a method of evaluation.

What We Do Not Know

Questions more pertinent to Washington State focus on the *specific* details of who is being served, what are their specific needs, and how these needs are being met specifically by early intervention services in Washington State. While these questions may be addressed by local assessment efforts (see Chapter 5), more work is needed to achieve knowledge *systematically*, on a *statewide* basis.

Such questions go well beyond the scope of this report. It became obvious early in this project, however, that good research could not separate the needs of families and children and the status of service delivery from studies assessing outcomes.

Washington State has already taken steps to answer the first question of who is being served. Child counts funded by the Infant Toddler Early Intervention Program and conducted by Research and Data Analysis provide a general description of the children and families receiving services. *Comprehensive information regarding the specific early intervention needs of children and families and the method of meeting these needs (program delivery) is lacking on a statewide level.*

The Importance of Knowing Needs for Research Results

While the outcomes chosen for this study were drawn from extensive methodological review of a variety of sources (see Chapter 2), they are general outcomes, and are not necessarily specific to Washington families. Since child and family needs are so varied, early intervention strategies differ for each family and child. Therefore, a key research component is to discover and document what the child and family's needs *are*. Using a hypothetical example, in one rural county, a child which requires specialized therapy must travel two hours to receive it. While the outcome, readiness to learn, may be extremely important, the family's more basic need is access to services. This need must be met *before* early intervention can even take place. Therefore, an outcome (which is program related) that is more specific to this Washington family would be access to services.

It may be demonstrated that certain needs are common to all families. For instance, evidence suggests the importance of creating community social support networks (which can be facilitated by early intervention program personnel) to forming secure home environments which positively affect child development (Dunst et al., 1997). A needs assessment should be conducted systematically on a statewide level, for conclusions to be drawn regarding these general needs in Washington State.

The Importance of Knowing Program Factors for Research Results

The importance of gaining a comprehensive, statewide view of program service delivery is twofold. The first importance relates to ascertaining whether basic needs are being met. As in the example above, before early intervention can take place, children with disabling or delaying conditions must have access to services. They also must have access to the *specific* services they require. It is critical to know whether these basic needs are being met by programs *before* assessment of outcomes takes place. For instance, one hypothetical family may have a child who could achieve maximum results with highly structured, intense services. A highly structured, intense program is available, but the family does not know about it. The child is therefore enrolled in a less structured program. If this child were assessed for developmental outcomes, results are unlikely to be as positive as if the child were enrolled in a more intense, structured program. While the conclusion drawn from an outcome study may be "the child showed slight improvement with this particular program" the important result to be ascertained here is that the child did not have access to the best possible services for his/her specific disability because the parent (and perhaps service provider) was unaware of services of this type.

The second importance of knowing what programs do before assessing outcomes relates to the necessity of measuring an outcome for services which the programs actually provide. For instance, if a researcher wants to examine the outcome, family empowerment, and the particular program curriculum the subject receives has not yet implemented a curriculum that incorporates family empowerment, then it is unlikely that the family will demonstrate characteristics of empowerment. With this result, one may be tempted to conclude that early intervention does not affect family empowerment, when in reality the situation indicates that family empowerment has not yet been incorporated in the curriculum—a far different conclusion. In sum, evaluation and even selection of outcomes should not be divorced from the actual delivery of program services.

Conclusions

Therefore, a well-designed outcome study would define outcome indicators *within the context of specific family and child needs*, and then incorporate *both* process measures and outcome measures in a manner that facilitates interpretation of study results. Not only would such a study reveal the strengths and weaknesses in a state's early intervention services, but also show how certain program elements are related to child/family outcomes. This conclusion is well-supported by the approach many states have chosen to evaluate their programs (see Chapter 4). From a review of various state consortiums, it is revealed that few states proceed with outcome measure studies before addressing three very basic questions: 1) who are the families and children receiving services, 2) what are

their needs, and 3) how are services meeting their needs. At present, many states have not gone beyond assessing these three questions (see Chapter 4).

Research options presented in this study have tried to address some of the above concerns within the designs themselves (see Chapter 7). Since important factors such as the specific needs of children and families in Washington and the status of program delivery are not established in detail on a statewide basis, development of outcome study designs was hampered. Without knowing the needs of children with disabling or delaying conditions and their families living in Washington State, the selection of outcomes became a generalized process. As discussed above, not knowing what services were provided to which children causes problems with attributing changes in child and family outcomes to early intervention. Since full scale program review was beyond the scope of this project, the details of which services children and families received were incorporated into the study designs only to the degree necessary to provide a minimal basis for attributing changes in outcomes to early intervention services. In some study designs, such information was not attainable in a consistent manner (see Chapters 7 and 8).

Needs assessment and program delivery review are studies that should be conducted separately for several reasons: 1) the results are important independent of outcome evaluation; 2) combining three goals (needs assessment, program delivery, and outcome assessment) in one study is methodologically complicated; 3) results are difficult to interpret for the reasons discussed above.

From a research prospective, a methodologically sound approach would be to collect information systematically, on a statewide level, which addresses four questions: 1) who are the children and families receiving services, 2) what are their needs, 3) how are programs addressing their needs, and 4) what child and family outcomes occur as a result of service provision. The research approach should provide a long-term, well-planned, integrated methodology. Research and Data Analysis offers a preliminary plan for review, discussion, and further refinement.

WASHINGTON STATE—RECOMMENDATIONS

General Recommendation

- To design an integrated research plan that logically and methodically addresses four questions:

    1) who are the children and families receiving services?
    2) what are their needs?
    3) how are programs addressing their needs?
    4) what child and family outcomes occur as a result of service provision?

What is an Integrated Research Plan?

While each of these questions could be addressed by independent research projects, an integrated approach would allow related aspects of these questions to be explored. In

terms of outcome assessments, a valid study could not be conducted *without* the consideration of the first three questions. In designing an integrated research approach, information from question one should be incorporated into the research methodology of question two. Similarly the results of the needs assessment should be incorporated into the research methodology of question three (program review). Finally, results from a needs assessment study and program review are essential to a well-defined outcome study. If outcome analysis is completed without these first steps, results would be at best inconclusive, and in the worst case, misleading.

The following is an outline of an integrated research plan that could be used in Washington State. The methodologies suggested for each step have been derived from the analysis of the strengths and weaknesses of each study design presented in Chapter 7. It was clear from a review of these study designs that each methodology contained certain strengths that are best suited to gathering information of a certain type. For instance, if part of the research question involves discovering the needs of families, it is clear that the family is a good source for this information. Whereas if part of the research question involves which specific therapy a child is receiving in a given time frame, the therapist is perhaps best equipped to provide this information. The following proposed methods are felt to be the most effective way of analyzing the designated research questions.

An Integrated Research Plan for Washington State

Step One: Who Are the Children and Families Receiving Services?

- Describe the children and families who are receiving early intervention in Washington State.

As mentioned before, the child counts conducted by Research and Data Analysis on behalf of the Infant Toddler Early Intervention Program provide much data in this respect. The data of these counts could be expanded to include an array of pertinent descriptive information on children with disabling or delaying conditions and their families who are receiving early intervention services in Washington State. The enhanced profiles of children and families enrolled in early intervention services would be valuable, and would contribute to the purpose of the integrated research plan. For example, it was reported at a meeting of the Advisory Group that more than half the children receiving early intervention services from one provider were in foster care. This anecdotal report highlighted the need to understand more about the characteristics of children receiving early intervention services. Foster care, enrollment in Supplemental Security Income (SSI), and mortality are examples of readily available population based measures that are pertinent to children enrolled in early intervention. The Data Inventory (see Chapter 6) described a number of readily available measures which could be linked to current and future child counts for a modest cost.

The enhanced profiles would contribute to the integrated research plan in two ways. First, the child count would provide a comprehensive subject pool for the selection of participants in the needs analysis study. Second, the information from the profiles would

provide descriptive information and some characteristics of the children and families participating in the integrated study.

Step Two: What Are Their Needs?

- Conduct a needs assessment of children and families who are receiving early intervention services in Washington State.

From the above child count, one thousand families and their service providers could be selected to participate in a statewide needs assessment study. The sample would be stratified by location (metro, small urban, and rural) to ensure statewide representation.

The best source of information for the needs of families are the families themselves. It would also be useful to ascertain whether needs that families express are consistent with what service providers perceive as family needs. Such information would be useful in conducting step three of the project that addresses how needs are being met. If service providers have different notions than families with regard to which needs are to be met by early intervention programs, services may be geared to fulfilling family needs as defined by service providers rather than fulfilling family needs as defined by the family.

The most efficient methodology for such a study uses focus groups, interviews, and a written survey. This methodology is described in detail in Key Informant Study—Three-tiered Approach in Chapter 7. A small number of parents (15) and service providers (15) will participate in separate focus groups and interviews to provide a descriptive context within which to interpret data from the thousand surveys, and to augment the profiles obtained in step one. A needs assessment survey will be sent to 1,000 families and their service providers to gather data for analysis of needs on a statewide level. The sample could be stratified by location of residence and type of disability. The results of the needs analysis will be to provide the basis for step three of the integrated research plan.

Step Three: How Are Services Addressing the Needs of Children and Families?

- Conduct a review of program services provided to children with disabling or delaying conditions and their families in Washington State.

From the 1,000 sampled for the needs assessment study, 300 children and families, and their service providers will be selected for the program review. As with the above study, the sample will be stratified by location (metro, small urban, rural) to ensure statewide representation. The needs of these children and families are already identified in step two. The research question for the study will address how these needs are being met.

One method discussed in the Child/Family Serves As Own Control studies that would be particularly useful in this study is the use of monthly service reports and program observation to obtain details about which services are being provided to which children and families. The monthly service reports would be completed by early intervention specialists for a period of one year. Services for a one-in-ten random sample of

participating children will be observed every two months to corroborate the monthly service reports and provide descriptive contextual information.

Step Four: What Child and Family Outcomes Occur as a Result of Service Provision?

- Conduct an outcome study which identifies positive child and family outcomes occurring as a result of early intervention services in Washington State.

Once the above steps have been completed, a relevant and thoughtful child and family outcome study could be conducted. This study should use the same 300 children and families used in the above study. In this way, *the profiles, needs, and services of the outcome study participants will be known already*. Further, descriptive data obtained from the needs assessment and program review will contribute to an understanding of the context within which outcomes should be interpreted. The methodologies and related problems would include those discussed throughout this report. Since the program characteristics are known for this group of children, conclusions regarding the outcomes of early intervention services can be drawn. Without knowing the service characteristics, it is difficult to attribute changes in outcomes directly to services (see previous section, The Importance of Knowing Program Factors for Research Results). The outcomes suggested in this report might be adopted along with those discovered in the needs analysis.

After completing the above steps, however, it may be decided that the benefits of an outcomes study might not be worth the time investment and money. Many other states have reached this conclusion (see Chapter 4). Such a decision does not indicate that child and family outcomes are not important—indeed they are the goal of the program. Given the difficulties in accurately measuring outcomes and in properly interpreting the data, however, many states have focused on studying program delivery systems in order to more efficiently meet the varied needs of families and children in their respective areas.

Timeline, Products, Cost

The comprehensive approach outlined above is a methodologically sound and resource efficient study design. It is estimated that should there be a commitment to address these questions, steps one through three will require at least two to three years to complete. After these steps are completed, an outcome study could take from one to ten years, depending on the nature of the study. A one year study would most likely be a cross-sectional study, a ten year one would most likely be longitudinal.

By integrating the steps and results of the research plan, costs per study are reduced in several ways. First, ground level background research would be conducted once, rather than numerous times. Second, organization is facilitated by an integrated study design, reducing time and money invested in planning. Third, many elements of the study can be conducted simultaneously which reduces time and costs.

The following tables present a hypothetical timeline for the completion of the integrated research plan for Washington State, a list of individual reports, and their estimated completion dates and costs.

INTEGRATED RESEARCH PLAN—POSSIBLE TIMELINE AND PRODUCTS

HYPOTHETICAL START DATE:		JUNE 1998			
Study Question	**By 12/1998**	**By 7/1999**	**By 12/1999**	**By 7/2000**	**By 12/2000**
Detailed outline for integrated research plan; preliminary research steps completed.*	X				
Who are the children and families receiving services?	Child Count	**Report**— *Child Count with Enhanced Profiles*			
What are their needs?		Subject selection complete (N=1,000) Focus Groups Survey developed	Surveys returned	**Report**— *Needs Assessment*	
How are programs addressing their needs?		Subject selection complete (N=300) Programs contacted Begin program review		End program review	**Report**— *Program Review*
What child and family outcomes occur as a result of service provision?		Subject selection complete (N=300)		Study design selected	Begin study
Ages of study subjects	B-3 years	1-3.5 years	1.5-4 years	2-4.5 years	2.5-5 years

* Hire staff, Human Resource Review Board

COST ESTIMATES

DELIVERABLES	DATE	ESTIMATED DIRECT COST
Report on Child Count and Enhanced Profiles	October 1999	$135,000
Needs Assessment Report	June 2000	$230,000
Program Review Report	December 2000	$305,000
Outcome Report	indeterminate	indeterminate

Considerations

This report has produced a series of recommendations. The primary purpose of the report was to design child and family outcome studies. A number of study designs were discussed in Chapter 7, and recommendations regarding an outcome study were made in Chapter 8. The need for a more comprehensive recommendation regarding an integrated research plan arose from the process used to complete the report's original intent. By meeting with parents, service providers, academic researchers, and program personnel, and by reviewing the literature and evaluation activities of state and federal government, several important issues became clear. First, assessing early intervention services occurs on multiple levels. The first level of assessment identifies and describes who is receiving services; the second identifies their needs; the third analyzes how services are meeting their needs; the fourth identifies the positive outcomes resulting from early intervention services. Second, each level is integrated so that evaluation of one level in isolation excludes critical information necessary for well-grounded data interpretation. For example, Hawaii's family needs assessment study could not answer the research question, are needs being met, when it was discovered that the program lacked information identifying what family needs *are* (see Chapter 4). Third, outcome research projects which do not take into account other fundamental elements (such as needs and program characteristics) produce results that are, at best, inconclusive.

From this information, it can be concluded that an integrated research plan is a methodologically sound and resource efficient approach to assessment. Addressing the question of outcomes before the groundwork for such research is complete will not produce sound results. Consequently, policy proceeding from such results will not be sound. It should be kept in mind that such policy decisions directly affect the lives of one of the most vulnerable populations the state of Washington has committed to protect—children with disabling or delaying conditions—and that decisions made now may affect these children and families for a lifetime.

REFERENCES

Achenbach, T. M., *and* Edelbrock, C. S. (1987). *Child behavior checklist*. Burlington: Author.

Accreditation Council on Services for People with Disabilities. (1995). *Outcome Measures for Early Childhood Intervention Services*. Towson: The Accreditation Council on Services for People with Disabilities.

Advisory Group Meeting, 5/15/98

Agee, L. C., Innocenti, M. S., *and* Boyce, G. C. (1994). *I'm All Stressed Out: The Impact of Parenting on the Effectiveness of a Parent Involvement Program*. Logan: Early Intervention Research Institute, Utah State University.

Ainsworth, M. D. S. (1973). The Development of Infant-mother Attachment. In B. M. Caldwell and H. Ricciutti (Eds.), *Review of Child Development Research* (pp. 1-94). Chicago: University of Chicago Press.

Andrews, H., Goldberg, D., Wellen, N., Pittman, B., *and* Struening, E. (1995). Prediction of Special Education Placement from Birth Certificate Data. *American Journal of Preventive Medicine, 11, No. 3*, 55-61.

Bagnato, Stephen J., Neisworth, John T., *and* Munson, Susan M. (1997). LINKing Assessment and Early Intervention. Baltimore: Paul H. Brookes Publishing Company Publishing Co.

Bailey, D. B., *and* Simeonsson, R. J. (1983). Design Issues in Family Impact Evaluation. In L. Bickman *and* D. L. Weatherford (Eds.), *Evaluating Early Intervention Programs for Severely Handicapped Children and Their Families* (pp. 209-230). Austin: Pro-Ed.

Bailey, D., Hebbler, K., Simeonsson, R., Spiker, D., *and* Wagner, M. (1998). Family Outcomes in Early Intervention: A Framework for Program Evaluation and Efficacy Research. *Exceptional Children, 64, No. 3*, 313-328.

Bailey, E. J., *and* Bricker, D. (1985). Evaluation of a Three-Year Early Intervention Demonstration Project. *Topics in Early Childhood Special Education, 5, No. 2*, 52-65.

Barnard K. E., Hammond, M., Booth, C., Bee H., Mitchell, S., *and* Spieker, S. (1989). Measurement and meaning of parent-child interaction. In F. Morrison, C. Lord *and* D. Keating (Eds.), *Applied developmental psychology, 3*. New York: Academic Press.

Barnard, K. E. (1978). *Nursing Child Assessment Teaching Scale* (NCATS). Seattle: University of Washington School of Nursing.

Barnard, K. E., *and* Kelly, J. F. (1990). Assessment of parent-child interaction. In J. P. Shonkoff *and* S. J. Meisels (Eds.), *Handbook of Early Childhood Intervention* (pp. 278-302). New York: Cambridge University Press.

Barnard, K. E. *and* Kelly J. F. (1990). *Nursing Child Assessment Teaching Scales* (NCATS) Assessment of parent-child interaction. In S. Meisels *and* J. Shonkoff (Eds.), *Handbook of early childhood intervention*. New York: Cambridge University Press.

Bayley, N. (1993). *The scales of infant development* (Second edition). New York: Psychological Corp.

Belsky, J. (1984). The Determinants of Parenting: A Process Model. *Child Development, 55*, 83-96.

Belsky, J., Hrncir, E., *and* Vondra, J. (1983). *Manual for the assessment of performance, competence, and executive capacity in infant play*. Unpublished Manuscript.

Bennett, F. C., *and* Guralnick, M. J. (1991). Effectiveness of Developmental Intervention in the First Five Years of Life. *Pediatric Clinics of North America, 38, No. 6*, 1513-1528.

Berrueta-Clement, J. R., Schweubgart. L. J., Barnett, W. S., Epstein, A. S., *and* Weikart, D. P. (Eds.). (1984). *Changed Lives: The Effects of the Perry Preschool Program on Youths Through Age 19*. Ypsilanti: High/Scope Press.

Billingsley, F. F., Gallucci, C., Peck C., Schwartz I. S., Staub, D. (1996). But Those Kids Can't Even Do Math: An Alternative Conceptualization of Outcomes for Inclusive Education. *Special Education Leadership Review*, 1-13.

Bowlby, F. (1969). *Attachment*. New York: Basis Books.

Boyce, G. (1993). The Effectiveness of Adding a Parent Involvement Component to an Existing Center-Based Program for Children with Disabilities and Their Families. In K. White *and* G. Boyce (Eds.), *Early Education and Development* (pp. 327-345).

Boyce, G. C., Smith, T. B., Immel, N., Casto, G. *and* Escobar, C. (1993). Early Intervention with Medically Fragile Infants: Investigating the Age-at-Start Question. In K. White *and* G. Boyce (Eds.), *Early Education and Development* (pp. 290-303).

Boyce, G. C., Behl, D., Mortensen, L. *and* Akers, J. (1991). Research Report-Child characteristics, family demographics and family processes: Their Effects on the Stress Experienced by Families of Children with Disabilities. *Counseling Psychology Quarterly, 4, No. 4*, 274-288.

Bricker, D. (1996). Assessment for IFSP Development and Intervention Planning. In S. J. Meisels *and* E. Feniches (Eds.), *New Visions for the Developmental Assessment of Infants and Young Children* (First edition, pp. 162-192). Arlington: Zero to Three, National Center for Clinical Infant Programs.

Bricker, D. (Vol. 1), Cripe, J., Slentz, K. *and* Bricker, D. (Vol. 2), (1993). *Assessment, Evaluation, and Programming System for Infants and Children* (AEPS) (Volumes 1 and 2). Baltimore: Paul H. Brooks Publishing Co.

Bricker, D. D., Bailey, E., *and* Bruder, M. B. (1984). The Efficacy of Early Intervention and the Handicapped Infant: A Wise or Wasted Resource. *Advances in Developmental and Behavioral Pediatrics, 5*, 373-423.

Bromwich, R. (1983). *Parent Behavior Progression - manual and 1983 supplement.* Northridge: The Center for Research Development and Services, Department of Educational Psychology, California State University.

Bruininks, Woodcock, Weatherman, *and* Hill (1985). *Scales of Independent Behavior*. Allen, TX: DLM Teaching Resources.

Burchinal, M. R., Bailey, D. B., *and* Snyder, P. (1994). Research Methods: Using Growth Curve Analysis to Evaluate Child Change in Longitudinal Investigation. *Journal of Early Intervention, 18, No.3*, 403-423.

Bzoch, K. R., *and* League, R. (1991). *The Bzoch-League Receptive-Expressive Emergent Language Scale: For the measurement of language skills in infancy* (Second edition). Baltimore: University Park Press.

Carey, W. B. *and* McDevitt, S. C. (1978). Revision of the infant temperament questionnaire. *Pediatrics, 61*, 735.

Carnegie Task Force on Meeting the Needs of Young Children. (1994). *Starting Points: Meeting the Needs of Our Youngest Children.* New York: Carnegie Corporation of New York.

Caro, P., *and* Derevensky, J. L. (1991). Family-Focused Intervention Model: Implementation and Research Findings. *Topics in Early Childhood Special Education, 11, No. 3*, 66-80.

Carr, J. (1987). Six Weeks to Twenty One Years Old: A Longitudinal Study of Children with Down's Syndrome and Their Families. *Child Psychology and Psychiatry, 29, No. 4*, 407-431.

Casto, G. C. (1986). Research and Program Evaluation in Early Childhood Special Education. In S. Odom *and* M. Karnes (Eds.), *Early Intervention for Infants and Children with Handicaps: An Empirical Base* (1988 edition, pp. 51-62). Baltimore: Paul H. Brookes Publishing Company.

Casto, G. C., *and* Lewis, A. (1984). Selecting Outcome Measures in Early Intervention. *Journal of the Division for Early Childhood, 10, No 2*, 118-123.

Casto, G. C., *and* Mastropieri, M. A. (1986). The Efficacy of Early Intervention Programs: A Meta-Analysis. *Exceptional Children, 52, No. 5*, 417-424.

Casto, G. C., *and* White, K. (1993). Longitudinal Studies of Alternative Types of Early Intervention: Rationale and Design. In K. White *and* G. Boyce (Eds.), *Early Education and Development* (pp. 224-235). Logan: Early Intervention Research Institute, Utah State University

Chugani, H. T., Phelps, M. E., *and* Mazziotta, J. C. (1987). Position Emission Tomography Study of Human Brain Functional Development. *Annals of Neurology, 22, No. 4*, 487-497.

Cleary, P. D. (1988). Social Support: Conceptualization and Measurement. In H. B. Weiss *and* F. H. Jacobs (Eds.), *Evaluating Family Programs* (pp. 195-216). Hawthorne: Aldine De Gruyter.

Colorado Foundation for Families and Children. (1997). Early Childhood Connections Family Survey: The Statewide Report.

Conger, J. A., *and* Kanungo, R. N. (1988). The Empowerment Process: Integrating Theory and Practice. *Academy of Management Review, 13, No. 3*, 471-482.

Crowley, S. L., *and* Taylor, M. J. (1993). *The Parenting Stress Index: Psychometric Characteristics with Families Having Disabled Children.* Logan: The Early Intervention Research Institute, Utah State University.

Crowley, S. L., *and* Taylor, M. J. (1994). Mother's and Father's Perceptions of Family Functioning in Families Having Children with Disabilities. *Early Education and Development, 5, No. 3*, 214-225.

Dawson, G., *and* Osterling, J. (1997). Early Intervention in Autism. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 307-326). Baltimore: Paul H. Brookes Publishing Company.

Devellis, R. F., Devellis, B. M., Revicki, D. A., Lurie, S. J., Runyan, D. K., *and* Bristol, M. (1985). Development and validation of the Child Improvement Locus of Control (CILC) Scales. In *Journal of Social and Clinical Psychology, 3*, 307-324.

Dihoff, R. A., Mcewan, M., Farrelly, M., Brosvic, G. M., Carpenter, L., Anderson, J., Kafer, L. B., Rizzuto, G. E., *and* Bloszinsky, S. (1994). Efficacy of Part- and Full-Time Early Intervention. *Perceptual and Motor Skills, 79*, 907-911.

Dodge, D. T. *and* Colker, L. (1992). *Creative Curriculum for Early Childhood* (Third edition). Washington DC: Teaching Strategies.

Dunst, C. J., Jenkins, V., *and* Trivette, C. M. (1984). The family support scale: Reliability and validity. In *Journal of Individual, Family, and Community Wellness, 1*, 45-52.

Dunst, C. J., Trivette, C. M., *and* Jodry, W. (1997). Influence of Social Support on Children with Disabilities and Their Families. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 499-522). Baltimore: Paul H. Brookes Publishing Company.

Dunst, C., Trivette, C., *and* Deal, A. (Eds.). (1988). *Enabling and Empowering Families*. Cambridge: Brookline Books.

Early Childhood Research Institute on Measuring Growth and Development. (1998). *Selection of General Growth Outcomes for Children Between Birth and Age Eight.* Technical Report # 1-DRAFT.

Eayrs, C., *and* Jones, R. P. (1992). Methodological Issues and Future Direction in the Evaluation of Early Intervention Programs. *Child Care, Health and Development, 18*, 15-28.

Eisen, M., Donald, C. A., Ware, J. E., Brook, R. H. (1980). *Conceptualization and measurement of health for children in the Health Insurance Study*. Santa Monica: The Rand Corporation.

Farran, D. C. (1990). Effects of intervention with disadvantaged and disabled children: A decade review. In J. Shonkoff *and* S. Meisels (Eds.), *Handbook of Early Childhood Intervention* (First edition, pp. 501-539). Cambridge: Cambridge University Press.

Fenson, L., Dale, P. S., Resnick, J. F., Thall, D., Bates, E., Hartung, J. P., Pethick, S., Reilly, J. S. (1993). *The MacArthur Communicative Development Inventory*. San Diego: Singular Publishing Group, Inc.

Fewell, R., *and* Glick, M. P. (1996). Program Evaluation Findings of an Intensive Early Intervention Program. *American Association on Mental Retardation, 233-243*.

Futterweit, L. R., *and* Ruff, H. A. (1993). Principles of Development: Implications for Early Intervention. *Journal of Applied Developmental Psychology, 14*, 153-173.

Gallagher, J. (1996). The family as a focus for intervention. In J. Shonkoff *and* S. Meisels (Eds.), *Handbook of Early Childhood Intervention* (First edition, pp. 540-559). Cambridge: Cambridge University Press.

Gibson, D., *and* Fields, D. L. (1984). Early Infant Stimulation Programs for Children with Down Syndrome. *Advances in Developmental and Behavior Pediatrics, 5*, 331-371.

Gibson, D., *and* Harris, A. (1988). Aggregated early intervention effects for Down's syndrome persons: patterning and longevity of benefits. *Journal of Mental Deficiency Research, 32*, 1-17.

Glover, E., Preminger, J., *and* Sanford, A. (1995). *Learning Accomplishment Profiles: Early Learning Accomplishment Profile (E-LAP)*. Chapel Hill: Chapel Hill Training-Outreach Project.

Goldberg, S. (1977). Social Competence in Infancy: A Model of Parent-Infant Interaction. *Merrill-Palmer Quarterly, 23, No. 3*, 163-176.

Green, B. L., & McAllister, C. (1998). Theory-Based, Participatory Evaluation: A Powerful Tool for Evaluating Family Support Programs, *Opening the Black Box*, Bulletin of Zero to Three, National Center for Clinical Infant Programs, *February/March, 1998*. Arlington: Zero to Three, National Center for Clinical Infant Programs.

Greenough, W. T., *and* Black, J. E. (1992). Introduction of Brain Structure by Experience: Substrates for Cognitive Development. *Minnesota Symposia on Child Psychology, 24*, 155-200.

Guralnick, M. J. (1988). Efficacy Research in Early Childhood Intervention Programs. In *Early Intervention for Infants and Children with Handicaps* (pp. 75-88). Baltimore: Paul H. Brooke.

Guralnick, M. J. (1989). Social competence as a future direction for early intervention programs. *Journal of Mental Deficiency Research, 33*, 275-281.

Guralnick, M. J. (1991). The Next Decade of Research on the Effectiveness of Early Intervention. *Exceptional Children, 58, No. 2*, 174-183.

Guralnick, M. J. (1993). Second Generation Research on the Effectiveness of Early Intervention. *Early Education and Development, 4, No. 4*, 366-378.

Guralnick, M. J. (1997). *The Effectiveness of Early Intervention*. Baltimore: Paul H. Brookes Publishing Company Publishing Co.

Guralnick, M. J. (1998). Effectiveness of Early Intervention for Vulnerable Children: A Developmental Perspective. *American Journal on Mental Retardation, 102(4):* 319-345.

Guralnick, M. J., *and* Bennett, F. C. (1987). Early Intervention for At-Risk and Handicapped Children: Current and Future Perspectives. In M. J. Guralnick *and* F. C. Bennett (Eds.), *The Effectiveness of Early Intervention for At-Risk and Handicapped Children* (pp. 366-382). New York: Academic Press.

Guralnick, M. J., *and* Neville B. (1997). Designing Early Intervention Programs to Promote Children's Social Competence. In Guralnick M. J. (Ed.), *The Effectiveness of Early Intervention*. Baltimore: Paul H. Brookes Publishing Company Publishing Co., pp. 579-610.

Hanson, M. J. (1985). An Analysis of the Effects of Early Intervention Services for Infants and Toddlers with Moderate and Severe Handicaps. *Topics in Early Childhood Special Education, 5, No. 2*, 36-51.

Harbin, Gloria *and* Kochanek, Thomas (1997). Cover letter to report. Frank Porter Graham Child Development Center.

Harding, E. *and* Keating B. (1995). *Birth To Three Years Study*. Olympia: Washington State Institute for Public Policy and Office of Legislative Budget Committee.

Harding, E. *and* Keating B. (1995). *Birth To Three Years Study: Technical Appendices*. Olympia: Washington State Institute for Public Policy and Office of Legislative Budget Committee.

Harris, S. R. (1997). The Effectiveness of Early Intervention for Children with Cerebrel Palsey and Related Motor Disabilities. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 327-348). Baltimore: Paul H. Brookes Publishing Company.

Hatton, D. D., Bailey, Jr., D. B., Burchinal, M. R., *and* Ferrell, K. A (1997) Developmental Growth Curves of Preschool Children with Vision Impairments. *Child Development, 68, No. 5*, 788-806.

Hauser-Cram, P (1990). Designing meaningful evaluations of early intervention services. In J. P. Shonkoff *and* S. J. Meisels (Eds.), *Handbook of Early Childhood Intervention* (pp. 583-602). New York: Cambridge University Press.

Hauser-Cram, P., *and* Krauss, M. W. (1991). Measuring Change in Children and Families. *Journal of Early Intervention, 15, No.3*, 288-297.

Hauser-Cram, P., *and* Shonkoff, J. P. (1988). Rethinking the Assessment of Child-Focused Outcomes. In H. B. Weiss *and* F. H. Jacobs (Eds.), *Evaluating Family Programs* (pp. 73-94). New York: A. de Gruyter.

Hayley, S. M., Coster, W. J., Ludlow, L. H., Haltiwanger, J. T., *and* Andrellos, P. J. (1992). *Pediatric Evaluation of Disability Inventory (PEDI)*. Boston: PEDI Research Group.

House Resolution 131, 105th Congress

http: //www.sri.com/policy/cehs/neils/neilprog.html, 3/13/98

http: //www.cec.sped.org/osep/8earlych.htm, 5/22/98

http: //www.ici.coled.umn.edu8001/ecri, 2/2/98

http: //www.isdd.indiana.edu/ fseval.html, 3/17/98

http: //www.nectas.unc.edu/eepcd/demos.htm#abstract, 5/22/98

Huttenlocher, P. R. (1990). Morphometric Study of Human Cerebral Cortex Development. *Neuropsychologia, 28, No. 6*, 517-527.

Innocenti, M. S. (1996). *Longitudinal Studies of the Effects of Alternative Types of Early Intervention for Children with Disabilities: Follow-up Institute*. Logan: Early Intervention Research Institute, Utah State University

Innocenti, M. S., Hollinger, P. D., Escobar, C. M., *and* White, K. R. (1992). The Cost-Effectiveness of Adding One Type of Parent Involvement to an Early Intervention Program. *Early Education and Development, 4, No. 4*, 306-326.

Kracke, K. R. (1981). A survey of procedures for assessing family conflict and dysfunction. *Family Therapy, 8*, 241-253.

Keenan, T., Hopps, D., Cawthon, L., Bowden, J., Dickey, R., Loerch, S., *and* Shureen, A. (1996). *Washington's Infant Toddler Early Intervention Program Study. A comparison of Enrollment Counts on December 1 1993, May 1, 1995, December 1, 1995 and May 1, 1996.* Olympia: Research and Data Analysis, Department of Social and Health Services.

Keenan, T., Lyons, D., Cawthon, L., Bowden, J., Dickey, R., Loerch, S., *and* Shureen, A. (1997). *Washington's Infant Toddler Early Intervention Program Study. Enrollment of Washington Children with Disabilities and Special Health Care Needs in Washington State Programs on December 2, 1996.* Olympia: Research and Data Analysis, Department of Social and Health Services.

Kelly, J. F., *and* Barnard, K. E. (in press). Assessment of parent-child interaction and implications for early intervention. In S. J. Meisels *and* J. P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention*. Cambridge: Cambridge University Press.

King, E. H., Logston, D. A., *and* Schroeder, S. R. (1992). Risk Factors for Developmental Delay Among Infants and Toddlers. *Children's Health Care, 21, No 1*, 39-52.

Kochanek, T. T., Kabacoff, R. I., *and* Lipsitt, L. P. (1987). Early Detection of Handicapping Conditions in Infancy and Early Childhood: Toward a Multivariate Model. *Journal of Developmental Psychology, 8*, 411-420.

Korsten, J. E., Dunn, D. D., Foss, T. V., *and* Francke, M. K. (1993). *Every Move Counts* (EMC). Antonio: Therapy Skill Builders/Psychological Corporation.

Lazar, I., *and* Darington, R. (1982). *Lasting Effects of Early Intervention: A Report from the Consortium for Longitudinal Studies.* Monographs of the Society for Research in Child Development 47 (Serial No. 195).

Lovaas, O. (1987). Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children. *Journal of Consulting and Clinical Psychology, 55*, 3-9.

Lyons, D., Keenan, T., Hopps, D., Cawthon, L., Dickey, R., Fleming, J., Loerch, S., *and* Shureen, A. (1998). *Washington's Infant Toddler Early Program Study: Enrollment of Washington's Children with Disabilities and Special Health Care Needs in Washington State Public Programs on December 1, 1997.* Olympia: Research and Data Analysis, Department of Social and Health Services.

Lyons-Ruth, K., *and* Zeanah, C. H. (1993). The Family Context of Infant Mental Health: I. Affective Development in the Primary Care Giving Relationship. In Zeanah, C. H. (Ed.), *Handbook of Infant Mental Health*. New York: Guilford Press, pp. 38-55.

Martin, E. W., Martin, R., *and* Terman, D. L. (1996). The Legislative and Litigation History of Special Education. *The Future of Children , 6, No 1*, 25-39.

McEachlin, J. J., Smith, T., *and* Lovvas, O. I. (1993). Long-Term Outcome for Children With Autism Who Received Early Intensive Behavioral Treatment. *American Journal on Mental Retardation, 97, No. 4*, 359-372.

McLean, L. K., *and* Cripe, J. W. (1997). The Effectiveness of Early Intervention for Children with Communication Disorder. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 327-348). Baltimore: Paul H. Brookes Publishing Company.

Meisels, S. J. (1986). *Using Criterion-Referenced Assessment Data to Measure the Progress of Handicapped Children in Early Intervention Programs.* Ann Arbor: University of Michigan.

Meisels, S. J., *and* Fenichel, E. (Eds.). (1996). *New Visions for the Developmental Assessment of Infants and Young Children* (First edition). Washington DC: Zero to Three.

Moore, M. (1998). Treatment Outcomes Project Launches Adult Data Collection. *ASHA Leader, 3, No. 4, February 3, 1998*, Rockville: American Speech-Language Hearing Association.

Moore, M., Fredericks, H. D., *and* Baldwin, V. (1981). The Long-Range Effects of Early Childhood Education on a Trainable Mentally Retarded Population. *Journal of the Division for Early Childhood, 4*, 94-110.

Mott, S., Lewis, M., Meisels, S. J., Shonkoff, J. P., *and* Simeonsson, R. J. (1986). Methods for Assessing Child and Family Outcomes in Early Childhood Special Education Programs: Some Views from the Field. *Topics in Early Childhood Special Education, 6, No. 2*, 1-15.

National Early Intervention Longitudinal Study Draft Parent Interview Survey, 1998

National Early Intervention Longitudinal Study Draft Surveys, February 27, 1997

Newborg, J., Stock, J., Wnek, L., Guidubaldi, J., *and* Svinicki, J. (1984). *Battelle developmental inventory*. Allen: DLM Teaching Resources.

Odom, S. I., *and* Shuster, S. K. (1986). Naturalistic Inquiry and the Assessment of Young Handicapped Children and Their Families. *Topics in Early Childhood Special Education, 6, No. 2*, 68-82.

Oelwein, P. L., Fewell, R. R., *and* Pruess, J. B. (1985). The Efficacy of Intervention at Outreach Sites of the Program for Children with Down Syndrome and Other Developmental Delays. *Topics in Early Childhood Special Education, 5, No. 2*, 78-87.

Office of Superintendent of Public Instruction (OSPI), (1997). Individuals with Disabilities Education Act—B Child Count December 1, 1997. Olympia: OSPI .

Palfrey, J. S., Singer, J. D., Walker, D. K., *and* Butler, J. A. (1987). Early Identification of Children's Special Needs. *Journal of Pediatrics, 11, No. 5*, 111-659.

Peck, C. A., Gallucci, C., Schwartz, I., Staub, D., White, O., *and* Billingsley, F. (1992). *Analysis of the outcomes of inclusive education and associated school contexts: A four year follow-along study.* Inclusive Schools Research Group-Washington State University, and University of Washington. Vancouver: Education Department, Washington State University.

Peck, C. A.. (1993). Ecological perspectives on the implementation of integrated early childhood programs. In C. A. Peck, S. L. Odom, *and* D. D. Bricker (Eds.), *Integrating young children with disabilities into community programs* (pp. 3-16). Baltimore: Paul H. Brookes Publishing Company Publishing Company.

Personal E-mail Communication, Beppie Shapiro, project coordinator, 4/6/98

Personal E-mail Communication, Beppie Shapiro, project coordinator, 1/6/98

Personal E-mail Communication, Jeff Priest, Early Childhood Research Institute research staff, 4/3/98

Personal E-mail Communication, Kathy Hebbeler, National Early Intervention Longitudinal Study coordinator, 4/17/98

Personal E-mail Communication, Michael Conn-Powers, researcher, 4/7/98

Personal Interview, Maryanne Barnes, executive director, Tacoma Learning Center, 3/24/98

Polit, D. F. *and* Hungler, B. P., (1987). *Nursing research* (Third edition). Philadelphia: L. B. Lippincott.

Presentation, Dr. Susan Janko, Researcher, 2/6/98

Ramey, C. T., *and* Haskins, R. (1981). The Modification of Intelligence Through Early Experience. *Intelligence, 5*, 5-19.

Ramey, C. T., Bryant, D. M., Sparling, J. J., *and* Wasik, B. H. (1985). Project CARE: A Comparison of Two Early Intervention Strategies to Prevent Retarded Development. *Topics in Early Childhood Special Education, 5, No. 2*, 12-25.

Ramey, C. T., Bryant, D. M., Wasik, B. H., Sparling, J. J., Fendt, K. H., *and* LaVange, L. M. (1992). Infant Health and Development Program for Low Birth Weight, Premature Infants: Program Elements, Family Participation, and Child Intelligence. *Pediatrics, 3*, 454-465.

Ramey, C. T., Stedman, D. J., Borders-Patterson, A., *and* Mengel, W. (1978). Predicting School Failure from Information Available at Birth. *American Journal of Mental Deficiency, 82, No. 6*, 525-534.

Resnick, M. B., Armstrong, S., *and* Carter, R. L. (1988). Developmental Intervention Program for High-risk Premature Infants: Effects on Development and Parent-Infant Interactions. *Developmental and Behavioral Pediatrics, 9, No. 2*, 73-78.

Riskin, J. *and* Faunce, E. E. (1982). Family Interaction Scales: I. Theoretical framework and method. *Archives of General Psychiatry, 22*, 504-512.

Roberts, R. N., Innocenti, M. S., *and* Goetze, L. D. (1997). *By What Outcomes Should Part H be Evaluated at the State Level?* Proceedings of the State Part H Evaluators' Consortium. Logan: Early Intervention Research Institute, Utah State University.

Rojahn, J., Aman, M., Moeschberger, M., King, E., Logsdon, D., *and* Schroeder, S. (1995). Biological and Environmental Risk for Poor Developmental Outcome of Young Children. *American Journal on Mental Retardation, 97, No. 6*, 702-708.

Sarason, I. G., Levine, H. M., Basham, R. B., *and* Sarason, B. R. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology, 44*, 127-139.

Segal, Marilyn, *and* Webber, Noreen T. (1996). Nonstructural Play Observations: Guidelines, Benefits, and Caveats. In S. J. Meisels *and* E. Fenichel (Eds.). (1996). *New Visions for the Developmental Assessment of Infants and Young Children* (First edition). Arlington: Zero to Three, National Center for Clinical Infant Programs.

Seifer, R., Clark, G. N., *and* Samaeroff, A. J. (1991). Positive Effects of Interaction Coaching on Infants with Developmental Disabilities and Their Mothers. *American Journal on Mental Retardation, 90, No. 1*, 1-11.

Shonkoff, J. P., *and* Hauser-Cram, P. (1987). Early Intervention for Disabled Infants and Their Families: A Quantitative Analysis. *Pediatrics, 80, No. 5*, 650-658.

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., *and* Upshur, C. (1988). Early Intervention Efficacy Research: What Have We Learned and Where Do We Go From Here? *Topics in Early Childhood Special Education, 8, No. 1*, 81-93.

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., *and* Upshur, C. C. (1992). *Development of Infants with Disabilities and Their Families: Implications for Theory and Service Delivery*. Monographs of the Society for Research in Child Development, *Serial No. 230, 57, No. 6.*

Snyder, K. D., Weeldreyer, J. C., Dunst, C. J., *and* Cooper, C. S. (1985). *Parent self-awareness scale*. Morganton: Western Carolina Center.

Songs, A., Jones, S., Lippert, J., Metzgen, K., Miller, J., *and* Borreca, C. (1984). Wisconsin Behavior Rating Scale: Measure of adaptive behavior for the developmental levels of 0 to 3 years. *American Journal of Mental Deficiency, 88*, 401-410.

Spiker, D., *and* Hopmann, M. R. (1997). The Effectiveness of Early Intervention for Children with Down Syndrome. In M. J. Guralnick (Ed.), *The Effectiveness of Early Intervention* (pp. 271-306). Baltimore: Paul H. Brookes Publishing Company.

Staples, L. H. (1990). Powerful Ideas About Empowerment. *Administration in Social Work, 14, No. 2*, 29-42.

Strom, R. (1984). Parent as a Teacher Inventory. Bensenville: Scholastic Testing Service.

Taylor, M. (1993). The Cost Effectiveness of Increasing Hours Per Week of Early Intervention Services for Young Children with Disabilities. In K. White *and* G. Boyce (Eds.), *Early Education and Development* (pp. 238-254).

Tjossem, T. D. (1976). Early Intervention: Issues and Approaches. In *Intervention Strategies for High Risk Infants and Young Children* (pp. 3-33). Baltimore: Baltimore University Park Press.

Turnbull, A. P., *and* Turnbull, H. R. (in press). Evolution of family professional models: Empowerment as the model for the early 21st century. In S. J. Meisels *and* J. P. Shonkoff (Eds.), *Handbook of Early Intervention* (Second edition). Cambridge: Cambridge University Press

Turnbull, A. P. *and* Turnbull H. R. (1997). *Families, Professionals, and Exceptionality: A Special Partnership*. Upper Saddle River: Prentice-Hall.

U. S. Department of Education Program Performance Plans (FY1999). (1998). Washington DC: U. S. Department of Education

U. S. Department of Health and Human Services. (1991). *Healthy People 2000: National Health Promotion and Disease Prevention Objectives.* Washington DC: Public Health Service.

Vaux, A., *and* Harrison, D. (1985). Support network characteristics associated with support satisfaction and perceived support. *American Journal of Community Psychology, 13*, 245-268.

Vulpe, S. G. (1994). *Vulpe Assessment Battery* (Revised edition). New York: Slosson Educational Publications.

Walsh, W. M., *and* Wood, J. I. (1983). Family Assessment: Bridging the gap between theory, research, and practice. *American Mental Health Counselor Association Journal*, 111-120.

Weiler, I. J., Hawrylak, N., *and* Greenough, W. T. (1995). Morphogenesis in Memory Formation: Synaptic and Cellular Mechanisms. *Behavioral Brain Research, 66*, 1-6.

White, K. R., *and* Casto, G. C. (1985). An Integrative Review of Early Intervention Efficacy Studies with At-Risk Children: Implications for the Handicapped. *Analysis and Intervention in Developmental Disabilities, 5*, 7-31.

White, K. R., Bush, D. W., *and* Casto, G. C. (1985). Learning From Reviews of Early Intervention. *The Journal of Special Education, 19, No. 4*, 417-428.

Wolery, M. (1985). The Evaluation of Two Levels of a Center Based Early Intervention Project. *Topics in Early Childhood Special Education, 5, No. 2*, 66-77.

Zero to Three, National Center for Clinical Infant Programs. (1992). *Heart Start: The Emotional Foundations of School Readiness.* Arlington: Zero to Three, National Center for Infant Programs.

Zigler, E., *and* Balla, D. (1982). Selecting outcome variables in evaluations of early childhood special education programs. *Topics in Early Childhood Special Education, 4*, 11-22.

APPENDICES

APPENDIX A

ADVISORY GROUP BIOSKETCHES

Nancy Anderson, M.D., M.P.H., is the lead consulting physician for the Medical Assistance Administration. She received her M.D. degree from Columbia University in 1980 and trained as a pediatrician at the University of Washington and Grady Hospital/Emory University. After working in Atlanta, she returned to Seattle to complete an M.P.H. in Health Services/Maternal Child Health. Subsequently she lived and worked in Mozambique for five years and in Portugal for three years. She is interested in women's health and community health assessment particularly in the international and intercultural contexts.

Nancy Fisher, R.N., M.D., M.P.H., is the Medical Director for the Medical Assistance Administration of DSHS. She began her health care career in the U.S. Navy Nurse Corps. In 1973 she started medical training at Baylor College of Medicine, where she received her M.D. and completed pediatrics internship and residency. In 1978 she began a Fellowship in Medical Genetics in the Department of Medicine at the University of Washington, where, as an R.W.J. Clinical Scholar, she also completed a residency in Preventive Medicine and earned an M.P.H. She is currently a Clinical Associate Professor in Pediatrics at the University of Washington. Her publications cover diverse topics in pediatrics, genetics, and cultural diversity. Dr. Fisher was named to *Who's Who in America* in 1986. She has a long history of community involvement and obtained a Certificate in Ethics from the University of Washington in 1993.

Jean Kelly, Ph.D., is a Research Associate Professor in the Department of Family and Child Nursing and an Adjunct Instructor in the Department of Special Education at the University of Washington. She received an M.A. from San Francisco State University and a Ph.D. from the UW, both in Early Childhood Special Education. She currently acts as the Principal Investigator of a birth to three early intervention grant and as Co-Principal Investigator on two grants (funded by the MCH Bureau and the NICHD) related to Early Child Care for Typically Developing Children and Children with Special Needs. Dr. Kelly serves on the Personnel Preparation Committee of the Infant-Toddler Early Intervention Program's Washington State Interagency Coordinating Council. She is the author of numerous journal articles and book chapters about parent-child interactions, particularly for young children with special needs.

Katy Middleton, B.S., received a B.S. in Biology from the University of Alaska in Fairbanks. Katy is the loving mother of Wilson Parrish Middleton, born 8/6/91. Wilson, born at 26 weeks, was diagnosed with hydrocephalus during his 121 days in the NICU. Since 1992, Katy has been active in the early intervention field. After moving to Yakima in 1995, she has been a member of the local ICC and has coordinated several public awareness efforts. Hired as an FRC in 1996, Katy assumed responsibility for coordinating the NICU follow up clinic, assisted in the design of the information system for Children's Village, served on the SICC Data Committee and participated in the Special Education Forum. In addition, she is currently implementing a new screening and reporting tool for use with birth to three year olds at Children's Village, serving as Secretary for the Parent to Parent Advisory Board and facilitating community inclusion efforts.

Paulette (Paulie) Mills, Ph.D., is an Assistant Professor, Department of Human Development at Washington State University (Pullman). She received an M.A. from the University of Minnesota in Child Psychology and a Ph.D. from the University of Washington in Education/Special Education. Prior to assuming her responsibilities at WSU, she served as Follow-Up Research Coordinator and Testing Coordinator for a number of studies at the UW Experimental Education Unit. She also was the Coordinator for the Rural Services Providers Project and subsequently received the Member of the Year Award (1991) of the American Council on Rural Special Education. At WSU, she has received numerous teaching awards. Her recent publications have focused on cognitive referencing, language facilitation, and assessment of program design characteristics.

Judith (Judi) Moore, M.A., has been Executive Director of Boyer Children's Clinic in Seattle since 1980. She received an M.A. in Counseling Psychology from Chapman College and a B.A. in Psychology from Willamette University. She has served as director of numerous projects including the At Risk Project (Asian Tracking and Referral by Interagency Seattle Committees), Extending Family Resources, Foster Extended Family Project, and Staff Training for Early Childhood Development Centers. As a legislative liaison her activities included passage of House Bill 1085 for neurodevelopmental therapy for children with disabilities, 1990. Judith was Chair of the State of Washington Interagency Council for Infants and Toddlers with Disabilities and Their Families from 1993 to 1996 and first Chairperson of the Early Childhood Development Association of Washington.

Charles (Cap) Peck, Ph.D., is Professor of Special Education at Washington State University (Vancouver). He began his career in education in Santa Rosa, California, as an instructional aide serving children with severe multiple handicaps. He earned his teaching credentials in elementary education and special education at Sonoma State University and his Ph.D. in Special Education and Educational Psychology at University of California, Santa Barbara. He came to WSU in 1984, serving first on the faculty in Pullman and then in Vancouver in 1989. His research projects have focused on the inclusion of children with disabilities in regular classrooms. Cap has authored or co-authored over fifty scholarly papers and edited two volumes related to children with disabilities. He was Teacher of the Year at WSU (Vancouver) in 1993 and received the College of Education Faculty Excellence Award for Research in 1995.

Susan Sandall, Ph.D., is Research Coordinator of the Early Childhood Research Institute on Inclusion at the University of Washington. Susan received her B.A. from the University of California, Berkeley, her M.A. from the University of Oregon, and her Ph.D. from the University of Washington College of Education. After completing her Ph.D., she was Research Assistant Professor at the University of Colorado and Associate Professor at the University of Delaware. She returned to the UW in 1996. She is co-author of two books, author or co-author of six book chapters and numerous journal articles. In Delaware, she was project director for the Evaluation of IRMC Sponsored Early Childhood Programs. She has served as a consultant and provided training on topics including adult-child interaction, intervention methods, and mainstreaming.

Kristine (Kris) Slentz, Ph.D., is Associate Professor, Special & Elementary Education, Western Washington University. Kris obtained her B.A. at the State University of New York in Sociology and her M.A. and Ph.D. at the University of Oregon in Special Education. She came to Western Washington University in 1989. She serves on numerous task forces and advisory boards and has

also been a consultant for a number of Educational Service Districts and for the Child Outcomes Project of the Nooksack Family Literacy Project. Her publications include journal articles and monographs, in particular about the Assessment, Evaluation and Programming System for Infants and Young Children.

PROGRAM STAFF

Lou Colwell, Ed.D, is program support supervisor for early intervention services, birth to three, at the Office of the Superintendent of Public Instruction. She has experience as a teacher (preschool through third grade) and director of early childhood programs in both the private and public sectors. Her present position focuses on providing technical assistance and training to assist school districts in implementing the Individuals with Disabilities Education Act (IDEA). Lou received her M.Ed. and Ed.D. from Seattle University.

Deborah A. Lee, Ph.D., R.N., is a Public Health Nursing Consultant for the Department of Health (DOH), Children with Special Health Care Needs Program. She received a B.S.N. from Western Kentucky University, a M. N. from Emory University, and a Ph.D. in Nursing from the University of North Carolina at Chapel Hill. Prior to her position at DOH, Dr. Lee completed a postdoctoral fellowship at the University of Washington School of Nursing, focusing on health policy and children with special health care needs. Dr. Lee has been involved with children with special health care needs and their families in many different capacities-as clinician, educator and researcher. Her research has focused on children with developmental delays, HIV, chronic illness, and most recently children who are medically fragile and technology-dependent.

Babs Roberts is a Grant Management Analyst for the DSHS Infant Toddler Early Intervention Program and responsible for monitoring its agreement with Research and Data Analysis. Babs has been with the Infant Toddler Early Intervention Program for 3 1/2 years and is currently responsible for coordinating contractual activities and federal reporting requirements. As part of her duties, she is responsible for annual data reporting required by the Office of Special Education Programs at the federal Department of Education. Babs is also responsible for coordination of data collection from contractors according to their annual work order requirements.

APPENDIX B

CHILD/FAMILY/PROGRAM CHARACTERISTICS

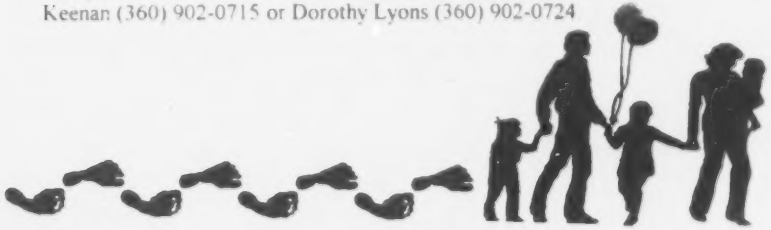
CHILD	FAMILY	PROGRAM
Age at Entry Age at Identification Apgar Score Attention Behavioral Characteristics Birthweight Blood lead Chronological Age Cognitive Function Condition Developmental Competence Diagnosis Differences Gender Gestational Age Health Status LBW Motivation Multiple trauma Peer Social Network Race Severity of Disability or Biological Risk Temperament Type of Disability or Risk	Age Community Culture Cultural Background Cultural Expectations Degree of Depression Domestic Violence Early Caregiver-Child Relationships External Social Supports Family Composition/Extended Family Family Perception of Disability and Risk Family Size Family Stress Family-Orchestrated Child Experiences Financial Resources Intergenerational Parenting Experiences Level of Education Marital Relationship Maternal Age Mental Health Status Parent Involvement Parental Attitudes Re Peer Relationships Parental Expectations Parental Locus of Control Parity Patterns of Interaction Physical Health Status Quality of Home Environment Quality of Parent-Child Interaction Resource and Information Needs Resources Within the Family Role of the Child in the Community Rural/Urban Safety Severity of Family Risk Social Support Socioeconomic Status Substance abuse Work on IFSP goals	Amount of Parent Involvement Attention to Individual Differences in Program Delivery Auxiliary Services Comprehensiveness Contact Time Degree of Family Counseling Degree of Structure Direct vs. Intermediary Service Provision Duration of Services Environmental Maintenance of Gains External Programs Family Connectedness IFSP Involvement Implemented vs. Intended Services Intensity Interdisciplinary vs Single Discipline Location of Services (home/center/ multiple) Onset of Services Parent Involvement Provider Competence Provider-Parent Relationship Single vs. Multiple Sites Timing of Services

APPENDIX C

Describe any additional activities in your school district which provide information on early intervention programs and their effects. Attach additional pages if necessary.

Please send completed surveys, with any enclosures you are willing to share, in the enclosed envelope to Trisha Keenan, Research and Data Analysis, DSHS, PO Box 45204, Olympia, WA 98504-5204

Thank you in advance for your time and your assistance. If you have any questions or would like more information, please contact Trisha Keenan (360) 902-0715 or Dorothy Lyons (360) 902-0724



LOCAL ASSESSMENT SURVEY

Child and Family Early Intervention Outcome Measures Planning Project

Your answers to this survey will increase understanding of early intervention issues and outcomes for children age birth to three with disabilities and their families in Washington State. The purpose of this survey is to gather information about research, assessment or tracking efforts in your school district. Thank you for your help.

Name: _____

Phone Number: (___) _____

Organization: _____

County: _____

Research and Data Analysis
DSHS

Name(s) of Program/Study	Has this program developed its own family or provider survey? If so, please enclose a copy.	Does this program have a process to track the progress of children and/or families receiving early intervention services? If so, please describe.	Does this program track the services received by children after they transition at age three (other than ITEIP Form A)? If so, please describe.

APPENDIX D

STATE AND NATIONAL EARLY INTERVENTION GOALS

National Goals

NATIONAL IDEA GOALS, PART H (1997)

- A child's potential for developmental delay is minimized
- A child's potential for continuing services is minimized when school age is reached
- A child's potential to live independently is maximized
- A family's potential to meet the needs of their infants is enhanced
- State and local agencies' abilities to meet the needs of historically underrepresented populations (e.g., minority, low-income, inner-city, rural) is enhanced.

NATIONAL STATE PROGRAM GOALS AS STATED IN IDEA (1997)

A statewide system shall include, at a minimum, the following components:

— A definition of the term `developmental delay ' that will be used by the State in carrying out programs under this part.

— A State policy that is in effect and that ensures that appropriate early intervention services are available to all infants and toddlers with disabilities and their families, including Indian infants and toddlers and their families residing on a reservation geographically located in the State.

— A timely, comprehensive, multidisciplinary evaluation of the functioning of each infant or toddler with a disability in the State, and a family-directed identification of the needs of each family of such an infant or toddler, to appropriately assist in the development of the infant or toddler.

— For each infant or toddler with a disability in the State, an individualized family service plan, including service coordination services in accordance with such service plan.

— A comprehensive child find system, including a system for making referrals to service providers that includes timelines and provides for participation by primary referral

— A public awareness program focusing on early identification of infants and toddlers with disabilities, including the preparation and dissemination by the lead agency designated or established under paragraph (10) to all primary referral sources, especially hospitals and physicians, of information for parents on the availability of early intervention services, and procedures for determining the extent to which such sources disseminate such information to parents of infants and toddlers.

— A central directory which includes information on early intervention services, resources, and experts available in the State and research and demonstration projects being conducted in the State.

— A comprehensive system of personnel development, including the training of paraprofessionals and the training of primary referral sources respecting the basic components of early intervention services available in the State, and may include--

    * implementing innovative strategies and activities for the recruitment and retention of early education service providers;
    * promoting the preparation of early intervention providers who are fully and appropriately qualified to provide early intervention services under this part;
    * training personnel to work in rural and inner-city areas; and
    * training personnel to coordinate transition services for infants and toddlers served under this part from an early intervention program under this part to preschool or other appropriate services.
- Policies and procedures relating to the establishment and maintenance of standards to ensure that personnel necessary to carry out this part are appropriately and adequately prepared and trained, including--
    * the establishment and maintenance of standards which are consistent with any State-approved or recognized certification, licensing, registration, or other comparable requirements which apply to the area in which such personnel are providing early intervention services; and
    * to the extent such standards are not based on the highest requirements in the State applicable to a specific profession or discipline, the steps the State is taking to require the retraining or hiring of personnel that meet appropriate professional requirements in the State; except that nothing in this part, including this paragraph, prohibits the use of paraprofessionals and assistants who are appropriately trained and supervised, in accordance with State law, regulations, or written policy, to assist in the provision of early intervention services to infants and toddlers with disabilities under this part.
- A single line of responsibility in a lead agency designated or established by the Governor for carrying out:
    * the general administration and supervision of programs and activities, and the monitoring of programs and activities used by the State to carry out this part, to ensure that the State complies with this part;
    * the identification and coordination of all available resources within the State from Federal, State, local, and private sources;
    * the assignment of financial responsibility to the appropriate agencies;
    * the development of procedures to ensure that services are provided to infants and toddlers with disabilities and their families under this part in a timely manner pending the resolution of any disputes among public agencies or service providers;
    * the resolution of intra- and interagency disputes; and
    * the entry into formal interagency agreements that define the financial responsibility of each agency for paying for early intervention services (consistent with State law) and procedures for resolving disputes and that include all additional components necessary to ensure meaningful cooperation and coordination.
- A policy pertaining to the contracting or making of other arrangements with service providers to provide early intervention services in the State, consistent with the provisions of this part, including the contents of the application used and the conditions of the contract or other arrangements.
- A procedure for securing timely reimbursements of funds used under this part.
- Procedural safeguards with respect to programs under this part.

— A system for compiling data requested by the Secretary that relates to this part.
— A State Interagency Coordinating Council.
— Policies and procedures to ensure that, consistent with section 636(d)(5)--
    * to the maximum extent appropriate, early intervention services are provided in natural environments; and
    * the provision of early intervention services for any infant or toddler occurs in a setting other than a natural environment only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment.

[The Individuals with Disabilities Education Act Amendments of 1997, "Part C--INFANTS AND TODDLERS WITH DISABILITIES, sec. 635, http://thomas.loc.gov/#laws, (P.L. 105-117) H.R. 5 -- Law Text -- Table of Contents: "Part C--Infants and Toddlers with Disabilities"]

IFSP GOALS AS DETERMINED BY IDEA (1997)

A statewide system shall provide, at a minimum, for each infant or toddler with a disability, and the infant's or toddler 's family, to receive--
— a multidisciplinary assessment of the unique strengths and needs of the infant or toddler and the identification of services appropriate to meet such needs;
— a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family 's capacity to meet the developmental needs of the infant or toddler, and
— a written individualized family service plan developed by a multidisciplinary team, including the parents, as required by subsection (e).
— Periodic Review.--The individualized family service plan shall be evaluated once a year and the family shall be provided a review of the plan at 6-month intervals (or more often where appropriate based on infant or toddler and family needs).
— Promptness After Assessment.--The individualized family service plan shall be developed within a reasonable time after the assessment is completed. With the parents' consent, early intervention services may commence prior to the completion of the assessment.
— Content of Plan.--The individualized family service plan shall be in writing and contain--
    * a statement of the infant's or toddler's present levels of physical development, cognitive development, communication development, social or emotional development, and adaptive development, based on objective criteria;
    * a statement of the family's resources, priorities, and concerns relating to enhancing the development of the family's infant or toddler with a disability;
    * a statement of the major outcomes expected to be achieved for the infant or toddler and the family, and the criteria, procedures, and timelines used to determine the degree to which progress toward achieving the outcomes is being made and whether modifications or revisions of the outcomes or services are necessary;
    * a statement of specific early intervention services necessary to meet the unique needs of the infant or toddler and the family, including the frequency, intensity, and method of delivering services;

* a statement of the natural environments in which early intervention services shall appropriately be provided, including a justification of the extent, if any, to which the services will not be provided in a natural environment;
* the projected dates for initiation of services and the anticipated duration of the services;
* the identification of the service coordinator from the profession most immediately relevant to the infant's or toddler's or family 's needs (or who is otherwise qualified to carry out all applicable responsibilities under this part) who will be responsible for the implementation of the plan and coordination with other agencies and persons; and
* the steps to be taken to support the transition of the toddler with a disability to preschool or other appropriate services

— Parental Consent.--The contents of the individualized family service plan shall be fully explained to the parents and informed written consent from the parents shall be obtained prior to the provision of early intervention services described in such plan. If the parents do not provide consent with respect to a particular early intervention service, then the early intervention services to which consent is obtained shall be provided.

[The Individuals with Disabilities Education Act Amendments of 1997, "Part C--INFANTS AND TODDLERS WITH DISABILITIES, sec. 636, http://thomas.loc.gov/#laws, (P.L. 105-117): H.R. 5 -- Law Text -- Table of Contents: "Part C--Infants and Toddlers with Disabilities"]

PROCEDURAL RIGHTS AS DETERMINED BY IDEA (1997)

Minimum Procedures.--The procedural safeguards required to be included in a statewide system shall provide, at a minimum, the following:

— The timely administrative resolution of complaints by parents. Any party aggrieved by the findings and decision regarding an administrative complaint shall have the right to bring a civil action with respect to the complaint in any State court of competent jurisdiction or in a district court of the United States without regard to the amount in controversy. In any action brought under this paragraph, the court shall receive the records of the administrative proceedings, shall hear additional evidence at the request of a party, and, basing its decision on the preponderance of the evidence, shall grant such relief as the court determines is appropriate.

— The right to confidentiality of personally identifiable information, including the right of parents to written notice of and written consent to the exchange of such information among agencies consistent with Federal and State law.

— The right of the parents to determine whether they, their infant or toddler, or other family members will accept or decline any early intervention service under this part in accordance with State law without jeopardizing other early intervention services under this part.

— The opportunity for parents to examine records relating to assessment, screening, eligibility determinations, and the development and implementation of the individualized family service plan.

— Procedures to protect the rights of the infant or toddler whenever the parents of the infant or toddler are not known or cannot be found or the infant or toddler is a ward of the State, including the assignment of an individual (who shall not be an employee of the State lead

agency, or other State agency, and who shall not be any person, or any employee of a person, providing early intervention services to the infant or toddler or any family member of the infant or toddler) to act as a surrogate for the parents.

— Written prior notice to the parents of the infant or toddler with a disability whenever the State agency or service provider proposes to initiate or change or refuses to initiate or change the identification, evaluation, or placement of the infant or toddler with a disability, or the provision of appropriate early intervention services to the infant or toddler.

— Procedures designed to ensure that the notice fully informs the parents, in the parents' native language, unless it clearly is not feasible to do so, of all procedures available pursuant to this section.

— The right of parents to use mediation in accordance with section 615(e), except that—

* any reference in the section to a State educational agency shall be considered to be a reference to a State's lead agency established or designated under section 635(a)(10);
* any reference in the section to a local educational agency shall be considered to be a reference to a local service provider or the State's lead agency under this part, as the case may be; and
* any reference in the section to the provision of free appropriate public education to children with disabilities shall be considered to be a reference to the provision of appropriate early intervention services to infants and toddlers with disabilities.

[The Individuals with Disabilities Education Act Amendments of 1997, "Part C--INFANTS AND TODDLERS WITH DISABILITIES, sec. 639, http://thomas.loc.gov/#laws, (P.L. 105-117): H.R. 5 -- Law Text -- Table of Contents: "Part C--Infants and Toddlers with Disabilities"]

NATIONAL CHILD HEALTH GOALS: BIRTH TO THREE

◊ Reduce growth retardation among low-income children aged 5 and younger to less than 10%
◊ Reduce to less than 10% the prevalence of mental disorders among children and adolescents
◊ Reduce homicides among children aged 3 and younger to no more than 3.1 per 100,000
◊ Reduce to less than 25.2 per 1,000 children the rising incidence of maltreatment of children younger than 18
◊ Reduce deaths among children aged 14 and younger to no more than 5.5 per 100,000
◊ Reduce drowning deaths among children aged 4 and younger to no more than 2.3 per 100,000
◊ Reduce residential fire deaths among children aged 4 and younger to no more than 520 emergency department treatments per 100,000
◊ Reduce nonfatal poisoning among children aged 4 and younger to no more than 520 emergency department treatments per 100,000
◊ Reduce asthma morbidity among children aged 14 and younger, as measured by a reduction in asthma hospitalizations to no more than 225 per 100,000
◊ Reduce the prevalence of blood lead levels exceeding 15 µg/dL and 25µg/dL among children aged 6 mos-5 yrs. To no more than 500,000 and zero respectively
◊ Reduce infant mortality rate to no more than 7 per 1,000 live births
◊ Reduce the prevalence of serious mental retardation in school-aged children to no more than 2 per 1,000 children.

- ◊ Reduce infectious diarrhea by at least 25% among children in licensed child care centers and children in programs that provide an Individualized Education Program (IEP) or Individualized Health Plan
- ◊ Reduce acute middle ear infections among children aged 4 and younger, as measured by days of restricted activity or school absenteeism, to no more than 105 days per 100 children
- ◊ Reduce pneumonia-related days of restricted activity for children aged 4 and younger to 24 days per 100 children
- ◊ Reduce iron deficiency to less than 3% among children aged 1 through 4 and among women of childbearing age
- ◊ Reduce to no more than 20% the proportion of children aged 6 and younger who are regularly exposed to tobacco smoke at home.
- ◊ Achieve for all disadvantaged children and children with disabilities access to high quality and developmentally appropriate preschool programs that help prepare children for school, thereby improving their prospects with regard to school performance, problem behaviors, and mental and physical health
- ◊ Increase use of occupant protection systems, such as safety belts, child safety seats, etc., to at least 95% of children aged 4 and younger who are motor vehicle occupants
- ◊ Basic immunization for children under 2-90%; in day care facilities-95%
- ◊ Increase to at least 75% the proportion of providers of primary care for children who include assessment of cognitive, emotional, and parent-child functioning, with appropriate counseling, referral, and follow-up, in their clinical practices
- ◊ Increase to at least 90% the proportion of all children entering school programs for the first time who have received an oral health screening, referral, and follow-up for necessary diagnostic, preventative, and treatment services
- ◊ Increase to at least 90% the proportion of babies aged 18 months and younger who receive recommended primary care services at the appropriate intervals
- ◊ Increase to at least 80% the proportion of providers of primary care for children who routinely refer or screen infants and children for impairments of vision, hearing, speech and language, and assess other developmental milestones as part of well-child care.
- ◊ Reduce average age at which children with significant hearing impairment are identified to no more than 12 months.
- ◊ Improving financing and delivery of clinical preventative services so that virtually no American has a financial barrier to receiving at a minimum, the screening, counseling, and immunization services recommended by the U.S. Preventative Services Task Force.

["Age-related Objectives", Healthy People 2000, National Promotion and Disease Prevention Objectives, US Dept. of Health and Human Services, Pub. No. (PHS) 91-50212, 1990, pp. 564-570]

GOALS FROM THE CARNEGIE FOUNDATION REPORT, *MEETING THE NEEDS OF YOUNG CHILDREN*

1) **Promote Responsible Parenthood** through:
   - Expanding education about parenthood in families, schools, and communities, beginning in the elementary school years but no later than early adolescence

- Providing comprehensive family planning, pre-conception, prenatal, and postpartum services and support as part of a minimum health care reform package
- Delaying adolescent pregnancy through the provision of services, counseling, support and age-appropriate life options
- Ensuring that all couples, when considering the possibility of having children, assess their age, health, and resources in order to avoid unnecessary risks and to provide a healthy environment for raising a child
- Directing state and local funds to initiate and expand community-based parent education and support programs for families with infants and toddlers

2) **Guarantee Quality Child Care Choices** by:
- Strengthening the Family and Medical Leave Act of 1993 by expanding coverage to include employers with fewer than fifty employees, extending the twelve-week leave to four to six months, and providing partial wage replacement
- Adopting family-friendly workplace policies such as flexible work schedules and assistance with child care
- Channeling substantial new federal funds into child care to ensure quality and affordability for families with children under three and making the Dependent Care Tax Credit refundable for low- and moderate-income families
- Providing greater federal incentives to states to adopt and monitor child care standards of quality
- Developing community-based networks linking all child care programs and providers offering parents a variety of child care settings
- Allocating federal and state funds to provide training opportunities so that all child care providers have a grounding in the care and development of children under three
- Improving salary and benefits for child care providers

3) **Ensure Good Health and Protection** through:
- Making comprehensive primary and preventive care services, including immunizations, available to infants and toddlers as part of a minimum benefits package in health care reform
- Offering home visiting services to all first-time parents with a newborn and providing comprehensive home visiting services by trained professionals to all families who are at risk for poor maternal and child health outcomes
- Expanding the Women, Infants and Children (WIC) nutritional supplementation program to serve all eligible women and children
- Making the reduction of unintentional injuries to infants and toddlers a national priority
- Expanding proven parent education, support, and counseling programs to teach parents nonviolent conflict resolution in order to prevent child abuse and neglect, and implementing community-based programs to help families and children cope with the effects of living in unsafe and violent communities
- Enacting stringent national, state, and local laws to control possession of guns

4) **Mobilize Communities to Support Young Children and Their Families** by:

- Focusing the attention of every community in America on the needs of children under three and their families, by initiating a community-based strategic planning process
- Experimenting broadly with the creation of family-centered communities through two promising approaches: creating family and child centers to provide services and supports for all families; and expanding and adapting the Head Start model to meet the needs of low-income families with infants and toddlers
- Creating a high-level federal group, directed by the President to coordinate federal agency support on behalf of young children and to remove the obstacles faced by states and communities in their attempts to provide more effective services and supports to families with young children
- Funding family-centered programs through the Community Enterprise Board in order to strengthen families with infants and toddlers
- Establishing mechanisms, at the state level, to adopt comprehensive policy and program plans that focus on the period from before birth through the first three years of a child's life

From: Starting Points, Carnegie Task Force on Meeting the Needs of Our Youngest Children, Carnegie Foundation, 1994
This text can be found in abridged form at the web site: http://www.carnegie.org/starting_points

NATIONAL EDUCATION GOALS

— promoting coherent, nationwide, systemic education reform
— improving the quality of learning and teaching in the classroom and in the workplace;
— defining appropriate and coherent Federal, State, and local roles and responsibilities for education reform and lifelong learning;
— establishing valid and reliable mechanisms for--
  * building a broad national consensus on American education reform;
  * assisting in the development and certification of high-quality, internationally competitive content and student performance standards;
  * assisting in the development and certification of opportunity-to-learn standards; and
  * assisting in the development and certification of high-quality assessment measures that reflect the internationally competitive content and student performance standards;
— supporting new initiatives at the Federal, State, local, and school levels to provide equal educational opportunity for all students to meet high academic and occupational skill standards and to succeed in the world of employment and civic participation;
— providing a framework for the reauthorization of all Federal education programs by--
  * creating a vision of excellence and equity that will guide all Federal education and related programs;
  * providing for the establishment of high-quality, internationally competitive content and student performance standards and strategies that all students will be expected to achieve;
  * providing for the establishment of high-quality, internationally competitive opportunity-to-learn standards that all States, local educational agencies, and schools should achieve;

* encouraging and enabling all State educational agencies and local educational agencies to develop comprehensive improvement plans that will provide a coherent framework for the implementation of reauthorized Federal education and related programs in an integrated fashion that effectively educates all children to prepare them to participate fully as workers, parents, and citizens;
* providing resources to help individual schools, including those serving students with high needs, develop and implement comprehensive improvement plans
* promoting the use of technology to enable all students to achieve the National Education Goals;

— stimulating the development and adoption of a voluntary national system of skill standards and certification to serve as a cornerstone of the national strategy to enhance workforce skills
— assisting every elementary and secondary school that receives funds under this Act to actively involve parents and families in supporting the academic work of their children at home and in providing parents with skills to advocate for their children at school.

["Goals 2000: Educate America Act", H.R.1804, Sec. 2 (http://thomas.loc.gov/#laws) Public Law 103-227 Goals 2000]

CARNEGIE TASKFORCE GENERAL HEALTH GOALS

Goals for Infants Under One Year

General

◊ evaluation and support immediately after delivery
◊ complete physical exam
◊ laboratory tests to screen for genetic disease and thyroid function
◊ diagnosis of treatment of general health problems, both acute and chronic
◊ preventative procedures (Gonococcal eye infection prophylaxis, vitamin K)
◊ services of a neonatal intensive care unit, as appropriate
◊ nutritional assessment and supplementation (as needed)
◊ bonding, attachment support and extended contact with parents (including rooming-in—if desired)
◊ linkage to continuous and comprehensive pediatric care after discharge
◊ home health services
◊ be alert for signs of abuse and neglect

Services for Children

⇒ History and systems review
  medical history
  social setting
  family background
  genetic assessment
  age and developmental stage
  potential problems
⇒ Complete physical exam

height/weight
head circumference
developmental/behavioral assessment
vision and hearing evaluation

⇒ Screening and laboratory tests
hemoglobin/hematocrit
tuberculin skin test
lead poisoning
parasites
screening for sickle cell and other blood disorders

⇒ Nutritional assessment and supplementation (as needed)
iron
vitamin D
fluoride

⇒ Immunizations

⇒ Diagnosis and treatment of general health problems

⇒ Home health services

Services for Families During Infant's First Year

⇒ Counseling and anticipatory guidance regarding
infant development and behavior
maternal nutritional needs
infant nutritional needs and feeding practices
home and automobile accident prevention
infant stimulationa and parenting skills (including risk of abuse or neglect)
immunizations
health-damaging behavior by parents, including substance abuse and smoking
continuous and comprehensive health care
recognition and management of illness
hygiene and first aid
child care arrangements
other relevant issues in response to parental concern

⇒ Counseling and appropriate treatment or referral as needed for parents
who have chronic health problems which affect heir parental capacity such as
handicapping conditions
substance-abuse problems
mental health problems (including maternal depression)
whose infant is seriously ill
whose infant has a chronic illness or handicapping condition
whose infant is or is about to be hospitalized

Health Education

⇒ Counseling and anticipatory guidance

⇒ Developing positive health habits

⇒ Using health services appropriately

⇒ Accessing community health and social services

Access-Related Services

⇒ Transportation as appropriate
- emergency
- regionalized perinatal or tertiary care network
- facilitate obtaining needed health services

⇒ Outreach services

⇒ Hotline, translator 24-hour service

⇒ Child care services to facilitate obtaining needed health services

Children From One to Three Years

Services for Children

⇒ Periodic health assessment
- History and systems review
  - medical history
  - social setting
  - family background
  - genetic assessment
  - age and developmental stage
  - potential problems
- Psychosocial history
  - peer and family relationships
  - child care progress and problems
- Complete physcial examination
- height/weight
- head circumference
- developmental/behavioral assessment
- vision and hearing evaluation
- Screening and laboratory tests
  - hemoglobin/hematocrit
  - tuberculin skin test
  - lead poisoning
  - parasites
  - screening for sickle cell and other blood disorders
- Nutritional assessment and supplementation (as needed)
  - iron
  - vitamin D
  - fluoride

⇒ Immunizations

⇒ Diagnosis and treatment of general health problems

⇒ Diagnosis and treatment of mental health problems both acute and chronic
- emotional disorders
- learning disorders
- behavioral disorders
- substance abuse

problems with family and peer group
⇒ Counseling and support services for children with chronic or handicapping conditions
⇒ Dental services, preventative and therapeutic
⇒ Home health services

Services for Children and their Families

⇒ Counseling and anticipatory guidance regarding
nutritional needs
home and automobile accident prevention
parenting skills (including risk of abuse or neglect)
immunizations
health-damaging behavior by parents, including substance abuse and smoking
continuous and comprehensive health care
physical activity and exercise
hygiene and first aid
child care arrangements
dental health
childhood antecedents of adult illness
child development
environmental hazards
other relevant issues in response to child and parental concern
⇒ Counseling and appropriate treatment or referral as needed for parents
who have chronic health problems which affect heir parental capacity such as
handicapping conditions
substance-abuse problems
mental health problems (including maternal depression)
whose child is seriously ill
whose child has a chronic illness or handicapping condition
whose child is or is about to be hospitalized

Health Education

⇒ Counseling and anticipatory guidance
⇒ Developing positive health habits
⇒ Using health services appropriately
⇒ Accessing social services and entitlements

Access-Related Services

⇒ Transportation as appropriate
emergency
regionalized or tertiary care network
facilitate obtaining needed health services
⇒ Outreach services
⇒ Hotline, translator 24-hour service

⇒ Child care services to facilitate obtaining needed health services

From: Starting Points, Carnegie Task Force on Meeting the Needs of Our Youngest Children, Carnegie Foundation, 1994
This text can be found in abridged form at the web site: http://www.carnegie.org/starting_points

State Goals

SPECIFIC INFANT TODDLER EARLY INTERVENTION PROGRAM GOALS

- Identify all infants and toddlers who are potentially eligible for services (Childfind and referral)
- Assist families and child to gain access to 1) early intervention services (Part H) and 2) other services [Family Resource Coordinators (FRCs)]
- Educate families as to their rights and the procedural safeguards of the program (FRCs)
- Determine initial and continuing eligibility (evaluation) (FRCs)
- Identify strengths and needs on an on going basis (assessment) (FRCs)
- Allow family to identify their concerns, priorities and resources (FRCs)
- Develop Individualized Family Service Plans (IFSP) (FRCs)
- Re-evaluate IFSPs (FRCs)
- Ensure smooth transition from Early Intervention Services to Special Ed. Programs or other services

[Source: Principles, Procedural Safeguards & Guidelines, ITEIP, DSHS, Feb.,1997]

APPENDIX E

POSSIBLE STATISTICAL MODELS FOR ANALYZING CHANGE WHEN CHILDREN/FAMILY SERVE AS OWN CONTROL

GROWTH CURVE ANALYSIS MODEL

Margaret (Peg) Burchinal, et al., "Research Methods: Using Growth Curve Analysis to Evaluate Child Change in Longitudinal Investigations" (1994). This specific study compared the effect of mix-aged learning environments on both children with disabling or delaying conditions and those without. The authors generally describe uses of growth curve analysis.

Definition: Growth curve analysis identifies patterns of change over time and tests whether the patterns are related to other factors (than treatment). It can: 1) describe patterns of change, 2) determine whether identified groups display different development patterns, 3) identify correlates of patterns of change.

Assumptions: a) structure of outcome measure does not change over time, b) outcome is measured in the same units over time, c) the outcome has a normal distribution and is measured at an interval/ratio level, d) homogeneity of variance exists with each group, e) adequate model (linear, quadratic, cubic) has been selected to represent patterns of change.

Method: Longitudinal. Data stronger if collected at more intervals and with larger numbers—particularly important for this model when accounting for "other" factors that may affect evaluation of the desirable outcome. Uses a hierarchical linear model (HLM).

Outcome: Developmental Age

Measurement: Batelle Overall Developmental Age scores

Comments:

Measurements occurring at infancy would have a hard time meeting criterion "a".

The statistical methodology of growth curve analysis is strong (according to the article).

Model is obviously better for comparing patterns of change (and we lack a good comparison group). For instance, in the study the children scored better than their comparison on scores, but their pattern of change was not statistically significant. While growth curve analysis could tell us that early intervention was a factor influencing a *pattern* of change, does not portray the changes themselves.

THE CHANGE SCORE MODEL (ALSO, GAIN SCORE, DIFFERENCE SCORE)

Simple score of T_2-T_1

Usually this model uses Developmental Age (DA).

Statistical problems [especially test *r* factor differentials (see Hauser-Cram, et al., "Measuring Change in Children and Families" 1991)]

Comments:

Does not account for development due to maturation.

DQ, (DA/CA) may be very useful (since chronological age development is accounted for).

Britain, Lee et al., "High-Risk Children Referred to an Early Intervention Development Program" (1995) suggests maintenance of a DQ score over time is a proper goal for early intervention. In most of these types of studies, the "posts" are relatively quickly after the "pres" (usually around 6 months). It is useful in portraying overall change. Problems with using DQ focus on the sensitivity (specifically the *lack* of sensitivity) of instruments when measuring change in children with disabling or delaying conditions.

INTERVENTION DQ

Compares pretest DQ to DQ *during intervention* as opposed to at posttest.

Intervention DQ=Posttest DA-Pretest DA/Length of intervention

Suggests that this calculation would show greater gains.

INTERVENTION EFFICIENCY INDEX

Ratio of months of developmental gain divided by months of service (e.g. 4 months of gain over 6 months of treatment=rate of development of .67)

Comments:
No comparison to rate of change before intervention

PROPORTIONAL CHANGE INDEX (PCI)

Compares rate of change to an assumed stable "average"
Assumption—ratio of chronological age to developmental age is stable (in the absence of intervention)
Rate of development= (DA @ T2)-(DA @ T1)/(Months between T1 & T2)
PCI=(Rate of development)/(ratio of T1, DA to T1, CA)
PCI=1—an average rate of growth (12 months growth in cognitive development for a child with an initial Bailey score of 100 would yield a rate of development of 1 and a PCI of 1)
PCI scores are then compared to this average.

Case	T1 Bayley Scores	T2 Bayley Scores	Rate of development	PCI
A	50	88	1.16	1.12
B	92	62	.58	.65

T1=enrollment
T2=12 months after
A is above average, B is below.

Comments:
No real support for the assumption. Really categorizes *rate* of change as opposed to gross change.

PREDICTED PERFORMANCE SCORE

Compares actual performance score to predicted performance score.

Predicted Performance Score:
1) Pretest Performance Age/Pretest CA = Previous Rate of Development
2) Previous Rate of Development x months of intervention = predicted months gain
3) Predicted months gain + pretest performance age = Predicted Performance Age

Example:
1) Child Y is 36 months and performs at 18-month level: 18/36=.5
2) Child Y is in intervention 6 months so s/he will gain 3 months
3) 3 + 18 = 21 months=Predicted Performance Age

RESIDUAL CHANGE SCORES

Compares predicted change score to actual change score.

Prediction: Performs a regression equation to predict change. Equation uses: a) individual's pretest score b) distribution of sample score at T1 c) relation between T1 score and T2 score for the entire sample (slope of regression) and d) distribution of scores at T2.

Residual change score is difference between the individual's actual and predicted score.

Comments:
This would tell whether a child changed more than expected, but a child could still improve, without changing as much as predicted, and end up with a "negative residual".

Research and Data Analysis
Report Number 7.95a